

# **THE EXPERIENCES OF HEARING SIBLINGS WHEN THERE IS A DEAF CHILD IN THE FAMILY**

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The material presented in this thesis is the original work of the candidate except as acknowledged in the text, and has not been previously submitted, either in part or in whole, for a degree at this or any other University.

## **Abstract**

When a child is identified as deaf, intervention services typically focus on parents and the deaf child. In New Zealand and globally, little has been written about the experiences of hearing siblings when there is a deaf child in the family. We know very little about how sibling relationships might be affected when one child is deaf (Marschark, 1997). It is still unclear whether hearing siblings experience negative affects when there is a deaf child in the family or whether relationships with deaf siblings are warm and close with a special understanding.

This study had five main objectives. The first objective was to examine the experiences of hearing siblings who had either grown up with a deaf sibling or whose sibling had lost their hearing later in life. The second objective was to consider the influence that parents and extended family members had on the hearing/deaf sibling relationship. The third objective was to establish whether society's perceptions of disability complemented the sibling/family's perceptions and what impact, if any, this had on the hearing/deaf sibling relationship. The fourth objective was to determine whether hearing siblings and their families formed connections with the Deaf community and what those connections involved. The fifth objective was to triangulate the data and establish whether there was commonality between the views of hearing siblings, Resource Teachers of the Deaf and Advisers on Deaf children.

This study employed a mixed methods research design. Six hearing siblings aged between 18 to 65 years living in a city in the South Island of New Zealand were interviewed. Six Advisers on Deaf Children and six Resource Teachers of the Deaf from

both the North and South Islands of New Zealand completed a survey based on the findings from the interviews.

The qualitative findings revealed that hearing siblings view their deaf sibling as typical and normal and it is only when they step outside the immediate family that they develop an awareness of disability. Furthermore, society for the most part continues to view disability or difference in a less than positive light. Significantly, the study's findings reveal that hearing siblings make a substantial and enduring contribution to the lives of their deaf siblings yet they continue to be overlooked by professionals and wider society. Accordingly, it is recommended that educators, professionals and agencies begin to actively involve hearing siblings in the services they provide to families of deaf children including hearing siblings attending Individual Education Plan (IEP) meetings, Keeping in Touch (KIT) Days and Deaf Awareness Week events held in special and mainstream schools.

# **Dedication**

*Barbara Mary Ray*

*1921-1991*

This thesis is dedicated to my mother, a very special lady who graduated from Cambridge University, England, during an era when women received their degrees in the mail while men attended graduation ceremonies.

Love you mum,

Liz xo.

## **Acknowledgements**

I would like to express my heartfelt thanks to Dr Dean Sutherland and Dr Billy O'Steen for their wonderful guidance and support over the past three years. Dean and Billy, it has been a privilege to have you as my senior and associate supervisors and I will be forever grateful for your wisdom, dedication, meticulousness, encouragement and kindness.

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Last but not least...Molly girl, fetch your lead from the cupboard, we are off to the beach!

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## **List of Abbreviations**

AODC – Adviser on Deaf Children.

CODA – Children of Deaf Adults.

IEP – Individual Education Plan.

KIT Day – Keeping in Touch Day.

NZSL – New Zealand Sign Language.

RTD – Resource Teacher of the Deaf.

UNCROC - United Nations Convention on the Rights of the Child.

# Chapter 1

## Introduction

In New Zealand and globally very little research exists on the experiences of hearing siblings when there is a deaf child in the family. While there is a modest amount of research on siblings and siblings of children with other disabilities, Marschark (1997) concludes, “We actually know very little about how sibling relationships might be affected when one child is deaf” (p. 174). Historically, research has tended to focus on the experiences of parents of deaf children and children of deaf adults rather than the experiences of hearing siblings. The lack of awareness around the experiences of brothers and sisters of children with a disability suggests a dearth of professional interest and investment (Murphy, 1979). Little has changed since Marschark’s and Murphy’s studies, particularly so within the New Zealand setting. The role that hearing siblings play and the valuable contribution they make to the lives of their deaf siblings has for the most part remained unrecognized globally by educators, professionals, service providers and society alike. Meeting the individual needs of families with deaf children and how this can be achieved will be one of the most significant research questions in the field for generations to come (Moore, Jethro & Dunn, 2001).

Despite the lack of research, it is apparent that the existence of deafness in a family has the ability to affect all areas of daily life (Wood, Jackson & Turnbull, 2004) including needing to decide upon different cultural identities, i.e., deaf and/or hearing (Bat-Chava, 2000), communication systems, approaches and modes (Eleweke & Rodda, 2000), family dynamics being adversely affected by the choice of assistive devices, i.e., cochlear implant vs. hearing aids (Freeman, Dieterich & Rak, 2002) and parent-child relationships

(Buchanan, 2006). Parents with children who are deaf may feel unsure about their parenting skills, struggle to access information that will assist them in making decisions and feel stressed by the time demands linked to intervention (Calderon & Greenberg, 1999). The stress levels of parents of deaf children are influenced by a variety of factors, including their financial position, the age of identification, the degree of hearing loss, language skills, communication style and measure of social support (Asberg, Vogel & Bowers, 2008; Meadow-Orlans, 1994; Pipp-Siegal, Sedey & Yoshinaga-Itano, 2002).

### **Purpose of the study**

Globally there is a significant gap in the research on the experiences of hearing siblings when there is a deaf child in the family. Accordingly, this study had five main objectives. The first objective was to examine the experiences of hearing siblings who have either grown up with a deaf sibling or whose sibling has lost his hearing later in life to determine whether they were similar to siblings of children with other disabilities, or whether they were markedly different. Certain family dynamics may occur in families where one or more children differ in hearing status and research by Pollard and Rendon (1999) found that the hearing status differences in mixed deaf-hearing families "...can be a cherished aspect of a family's diversity or a stage upon which family conflicts are acted out" (p. 156).

The second objective of the study was to consider the influence that parents and extended family members had on the hearing/deaf sibling relationship. The third objective was to establish whether society's perceptions of disability complemented the sibling/family's perceptions and what impact, if any, this had on the hearing/deaf sibling

relationship. The fourth objective was to determine whether hearing siblings and their families formed connections with the Deaf community and what those connections involved. The fifth objective was to triangulate the data and establish whether there was commonality between the views of hearing siblings, Resource Teachers of the Deaf and Advisers on Deaf children.

This inquiry will explore the different links between hearing and deaf siblings and whether they change at various stages of a hearing sibling's life. Parental and extended family roles will be discussed in terms of their influence on developing positive or negative outcomes for hearing siblings. Society's view on deafness and disability will also be examined to clarify the impact commonly held beliefs might have on hearing siblings' experiences as research has generally portrayed the experiences of hearing siblings as negative (Tattersall & Young, 2003)

In providing a more current contribution to the field, this study will augment the small body of research carried out in the 1990s and the early and late 2000s. By acknowledging the important role that siblings play in the family system (Moore et al., 2001) it is hoped that educators, professionals and agencies will begin to reflect more on their own teaching practice, the assistance they provide to families and how this could be enhanced when identifying and meeting families' individual needs, particularly with regard to the contributions made by hearing siblings. When deciding upon the best means of supporting families, service providers should be cognizant of the findings of the World Health Organisation in their World Report on Disability (2011) which states that "Many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life activities" (p. xxi). This research examines the

experiences of hearing siblings when there is a deaf child in the family and contrasts these experiences with the views and knowledge of deaf education professionals.

## **Overview of the thesis**

There is a paucity of research in New Zealand and globally on the experiences of hearing siblings when there is a deaf child in the family. Thus, this study will provide a unique contribution to the literature. A brief outline of the study follows, which indicates the key themes that will be examined, together with the significance this study will have for educators, professionals and agencies working in the field.

Chapter 2 reviews the literature on siblings, siblings of children with a disability and siblings of children who are deaf or hearing impaired. The family systems approach and Bronfenbrenner's (1995) bio-ecological model of human development are utilized to highlight how the child and family comprise a system that is influenced by interactions between individuals and their environment over time. Lastly, societal attitudes towards disability are explored to establish the influence they have on the experiences of hearing siblings.

Chapter 3 describes the mixed methods design of the research project including the enlistment of participants, ethics approval, collection and analysis of the data.

Chapter 4 reports on the findings using Bronfenbrenner's (1979) ecological model as a framework to identify the different themes. Links are made to the similarities and differences in findings from other research.

Chapter 5 discusses the significance of the findings, the limitations of the study, proposed future direction for research and draws a conclusion on the implications for practice.



## **Chapter 2**

### **Literature Review**

#### **Introduction**

The following chapter provides a review of the literature on siblings, siblings of children with a disability and hearing siblings of deaf children. As there is limited research both in New Zealand and globally on hearing siblings of deaf children, the experiences of siblings and siblings of children with other disabilities are employed as a foundation for understanding sibling relationships. Comparisons can then be drawn between the experiences of the three distinct groups.

#### **Siblings**

##### **Sibling relationships**

Human beings look to make social connections from birth. A child's first attachment figure is its primary caregiver, typically its mother (Bowlby, 1969) and from this secure foundation affable siblings can become the focus of attachment. Siblings rely on each other for companionship and comfort (Goetting, 1986) and it comes as no surprise that the sibling relationship is one of the longest and most significant relationships in an individual's life (Baumann, Dyches & Braddick, 2005). In spite of years of research the sibling relationship with all its facets continues to remain unclear (Dunn, 2005). A full consideration of the research into sibling relationships follows in order to provide a basis for investigating the relationships of hearing and deaf siblings (Stoneman & Berman, 1993).

Sibling relationships are exceptional in a number of ways. Firstly, they are emotionally open which can intensify siblings' influence on each other. Secondly, the period spent with siblings is greater than that spent with parents. Lastly, there is significant variation in the degree to which brothers and sisters relate positively to each other (Pike, Coldwell & Dunn, 2005). While some parents may feel that their children's formative years have amounted to a sibling combat zone, Dunn (2005) assures us that sibling relationships can provide stability and consistency, albeit the influence depending on the degree to which the sibling is liked. Positive features from a parent-child relationship will also influence sibling relationships (Brody, Stoneman & McCoy, 1994). Equally however, when the relationship between a parent and child is difficult this can engender hostile sibling relationships.

Many parents will have lost sleep over the perceived impact of introducing a new sibling to their firstborn. In actuality, the birth of a sibling can be a problematic event for children. The younger the child's age at the birth, the more angst the child may feel at being displaced (Kramer & Gottman, 1992). Sibling life events are molded by birth order and gender (Silver & Frohlinger-Graham 2000) with older siblings playing a dominant role and this starts at the birth of the younger child.

Siblings experience their sibling relationship in different ways, depending on whether they are the older or younger offspring. Older siblings generally orchestrate interactions and educate younger siblings, while younger siblings tend to be the recipients of teaching and nurturing (Volling, 2012). An older sibling's conduct towards the newborn forecasts the younger child's behaviour within the sibling relationship later on in life (Dunn & Kendrick, 1982). Younger siblings generally seek assistance and encouragement from older sisters more than older brothers. Older sisters are inclined to demonstrate more

fostering, affection, closeness and collaboration than older brothers (McHale, Whiteman, Kim & Crouter, 2007) and compared with older brothers are more amicable and upbeat towards younger brothers than younger sisters (Dunn et al., 1982).

Siblings' daily interactions and familiarity, their emotionally unconstrained relationship and the affect of sharing parents all suggest that the relationship has developmental influence (Dunn, 2005). It is recognized that sibling relationships shape children's social and behavioural growth (Fussell, Macias & Taylor, 2005) playing a crucial part in their social understanding by promoting the development of social skills (Dunn, 1999). When the family living room descends into a sibling combat zone it is worth remembering that sibling relationships involve competition and disagreement as well as affection and camaraderie and increase children's ability to understand one another (Collins & Gunnar, 1990). While there is limited research on sibling rivalry, it has been noted that siblings engage in wide-ranging social comparisons between themselves and their siblings, including how their parents deal with them as opposed to their siblings (Whiteman, McHale & Soli, 2011).

Significantly, when children are undergoing traumatic life events, positive sibling relationships are a key source of support (Gass, Jenkins & Dunn, 2007). In an American study by Stewart (1983) where younger siblings were left in an unfamiliar situation with a stranger, without their mother but with an older sibling present, more than half of the older siblings were protective and loving towards their younger sibling and were successful in reducing the younger sibling's distress. This key source of support transpired regardless of the quality of the parent-child relationship (Stewart, 1983). When children have an affirmative and warm sibling relationship this can also help to protect them from the harmful affects of matrimonial conflict (Jenkins & Smith, 1990).

## **The family and ecological systems approach**

The family and ecological systems approach (Nichols & Swartz, 1998) depicts the family as an interactive system where what impacts one member of the family affects all members of the family. Something as commonplace as attending a child's medical appointment can have ramifications for other members of the family including having to alter parental working hours, child care arrangements for siblings and transportation considerations. Similarly, Bronfenbrenner's (1979) bio-ecological model of human development suggests that the child and family comprise a system that is influenced by interactions between people and environments over time. The sensory, linguistic and cultural difference of a family gives meaning to its experiences and this process continues throughout life.

Social learning processes can be used to effectively consider and determine the dynamics of sibling relationships (Whiteman et al., 2011). According to social learning theories individuals develop key behaviours, including cognitive behaviours such as attitudes and beliefs through two important means, reinforcement and observation of others' behaviours (Bandura, 1977). It is common sense that children will emulate their parents in the way they perceive or respond to life-changing events. Children imitate their parents' behavior in their exchanges with siblings indicating the interactive nature of families (Pike, et al., 2005).

Social learning principles suggest that modeling processes in sibling relationships vary, with older and same gender siblings more likely to act as models (Dunn, 2005). If for example the elder sibling is an active sportsperson then the younger sibling may be swept up in those experiences and be influenced by his elder sibling's success or failure. Some examples of siblings achieving at a high level in the same field of endeavour are the

Finn brothers, two talented New Zealand musicians, Valerie and Steven Adams and Barbara and Bruce Kendall, who are each New Zealand sporting greats.

A family systems approach underscores the active nature of family configuration and process. In particular, a family's capacity to be resilient or adjust in response to changes in internal and external needs and circumstances, including the development of individual family members (Dunn, 2005). Life-changing events may not necessarily be viewed as catastrophic when a family is able to adjust to or absorb change by adopting a "run of the mill" approach. An abundance of broad familial support, optimism within the parent-child relationship and consistent and respectful discipline of children all buffer children and adolescents from the turmoil that can be caused by life events (Youngstrom, Weist & Albus, 2003).

Children learn social competencies in their interactions with their parents and siblings and also through studying family members' interactions with others (Dunn, 2005). For example, many an adult has commented ruefully on how much like their parents they sound when dealing with familial situations. "The apple did not fall far from the tree" is a familiar cliché that is commonly used to describe this phenomenon. When parents treat siblings equally, adult sibling relationships are more likely to be positive (Boll, Ferring & Filipp, 2003).

The sibling relationship is the longest relationship individuals will experience in their lifetime and the dynamics of that relationship alter and can be more significant at different stages of the life span. This has been noted during transition periods such as childhood to adolescence and adolescence to adulthood when relationships become more voluntary and peer-like (Whiteman et al., 2011). Interestingly, during adolescence parents will spend more time with offspring of the same gender (Tucker, McHale & Crouter,

2003). Furthermore, children whose fathers or other male figures are at hand in the home have much better academic records than children without a male role model (Calderon & Low, 1998).

In summary, the sibling relationship is significant because of its uniqueness and longevity. The key elements of sibling relationships are:

- Sibling relationships are entirely unique (Pike et al., 2005).
- They can influence a child's development, give stability and consistency or form the basis for conflict (Dunn, 2005).
- Siblings are crucial in the lives of individuals and families worldwide and across the life span (Whiteman et al., 2011).
- They act as companions, sounding boards and role models in childhood and adolescence (Dunn, 2007).
- Siblings are resources of support throughout adulthood (Connidis & Campbell, 1995).
- Broad familial support, optimism within the parental-child relationships and unswerving parental discipline all buffer children and adolescents from life-changing events (Youngstrom et al., 2003).

How comparable or disparate are the experiences of siblings and siblings of children with disabilities? The following section reviews the literature on siblings of children with disabilities with the objective of understanding the various commonalities and differences shared with peers.

## **Siblings of children with disabilities**

### **Quality of life**

Understanding the experience of being a sibling of a child with a disability entails the unpacking of a sibling's view of his or her quality of life and the impact on the family system as a whole (Moyson & Roeyers, 2011). Quality of life is defined as having a life that is enjoyable and meaningful for an individual. Research suggests that siblings of children with a disability may define their quality of life differently from their parents. Parents of children with a disability tend to report more sibling adjustment problems and a greater negative impact on family social functioning than siblings (Moyson & Roeyers, 2011). Those siblings who do report negative adjustment problems are more likely to be young and male (Guite, Lobato, Kao & Plante, 2004). A Belgium-based study of siblings of children with disabilities aged between 6-14 years described 9 domains of quality of life: joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support and dealing with the outside world (Moyson & Roeyers, 2011). Through siblings using self-reporting (in earlier sibling studies researchers would ask mothers for their views rather than siblings directly) it was revealed that a child with a disability had an influence not only on the family members but also on the family system within the 9 domains of quality of life (Moyson & Roeyers, 2011). Within these 9 domains of quality of life: joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support and dealing with the outside world, the participants in the study were able to differentiate between the elements influencing their quality of life as a child and elements

influencing their quality of life as a child with a sibling with a disability (Moyson & Roeyers, 2011).

Participants said they valued the opportunity to do “typical” things with their disabled sibling, even when this meant having to adapt the activity to meet the needs of their sibling. They wanted the opportunity to look inside the minds of their sibling with a disability to comprehend what they desired, did or felt. Although participants in the study enjoyed doing things with their sibling they also wanted exclusive time with their parents, to do things without their disabled sibling and to have an area of their own at home (Moyson & Roeyers, 2011).

Siblings described acceptance of their disabled sibling as a very important element of sibling quality of life. Acceptance of their sibling with a disability enabled the participants to cope with unique situations as well as benefit from them, to take part in activities that would not normally come their way. Participants noted that sometimes the behavior of their disabled sibling was not pleasing. As a result they developed strategies to cope with this, such as ignoring the behavior, trying to comprehend it, or adapting to it. Participants in the study stated that it was okay to have a sibling with a disability as long as he was well, that they worried about their sibling’s mental and physical well-being (Moyson & Roeyers, 2011).

Participants felt that having the opportunity to meet other siblings with a brother or sister with a disability affected their sibling quality of life. These interactions helped participants to understand and accept their own experiences and put them into proportion. Significantly, participants did not see the purpose of these meetings as being a time for solving sibling difficulties (Moyson & Roeyers, 2011).



Participants also sought support from close relatives and friends. There was a feeling that though friends would never fully understand them they were important because they helped the participants to forget at times that they were a sibling. Finally, support from the outside world was meaningful when individuals appreciated their sibling with a disability and accepted the problematic situations participants sometimes went through (Moyson & Roeyers, 2011).

### **Understanding and acceptance of disability**

Very little data has been gathered on how and when siblings begin to comprehend that they have a brother or sister with a disability. There are few studies that have examined siblings' perceptions of impairment and disability or their understanding of diversity in regard to their brother or sister (Stalker & Connors, 2003). Nonetheless, it has been established that children aged 2-4 years can recognize significant physical or cognitive disabilities, as in the case of a 2-year-old with a sibling with Down's Syndrome who was able to point out another child with Down's Syndrome at a shopping mall. Typically, a sibling's grasp of disability may not occur until around 7 years old (Hames, 2008).

Parents of children with disabilities report that enlightening siblings about their disabled sibling is never a one-off occurrence and has to be repeated over time (Hames, 1997; 1998). Before sharing information, parents often wait and judge the developmental level of their children, making certain that they are able to understand any discussion about their sibling's disability. The majority of parents report that siblings demonstrate little response to the information (Gath, 1978).

A sibling's level of interest in receiving information about their disabled sibling is age related. Young children want to know how critical a disability is, adolescents or young adults are keen to know their own genetic tendencies and adults seek information so that they can explain their sibling's disability to their own offspring (Cramer, Erzkus, Mayweather, Pope, Roeder & Tone, 1997).

Many siblings have no idea during their first years of schooling if they are older or younger than their older disabled sibling. Despite being the younger sibling they are often instructed to take on a caregiving role and monitor their older disabled sibling (Hames, 2008). Consequently, some siblings can be confused regarding their birth order. However, most siblings are aware that being disabled is a lasting condition for their siblings (Hames, 2008).

Despite having an awareness of impairment, siblings do not appear to feel any significant difference between themselves and their disabled sibling (Stalker & Connors, 2003). Siblings describe their disabled brothers and sisters as having unique attributes rather than an impairment or disability. There is also a healthy level of exasperation and competition between siblings and disabled siblings (Stalker & Connors, 2003).

Many siblings have reported that they are aware of disapproving responses to their disabled siblings including name-calling, staring, condescending comments and misguided sympathy (Thomas, 1999). As a result, siblings may take on the parental role of providing reassurance and security to their disabled brother or sister during stressful life events (Gass et al., 2007).

An interview-based study in the United States by Singer (2002) of 15 adults with a disability found that these individuals realised during early to middle childhood that society held them in low regard. In complete contrast, their families treated them as typical

siblings, permitted them to take chances and were crucial in their developing positive identities, a sense of worth and autonomy. Additionally, disabled and non-disabled friends, supportive teachers and advisers were identified as being central to their development (Singer, 2002).

While a number of early studies suggest that having a sibling with a learning disability psychologically damages siblings (Hames, 2008), more recent studies have found that any harmful affect on siblings is usually minor. The variation between siblings of children with an intellectual disability and comparison siblings with regard to their overall psychological adjustment was small at best (Rossiter & Sharpe, 2001). Factors that influence how well siblings adjust include the amount of information they are provided (Boland, 2000), their sibling's behavioural difficulties and general family psychological resources (Taylor et al., 2001). Parental influence is strong in how siblings view their disabled brother or sister as attitudes towards the disabled sibling mirror that of the parents (Verte, Roeyers & Buysse, 2003). Significantly, siblings can experience uncertainty about the guardianship of their disabled sibling (Cramer et al., 1997).

A United Kingdom study in which 24 children aged 6-19 years were asked to describe their disabled sibling found that young children did not refer to disability at all and older children explicitly said that they did not see their disabled sibling as different, instead many described their sibling as "normal" (Stalker & Connors, 2003). While some children did view their disabled sibling as "different" there was no negative connotation attached to this because "different" was normal to them. A Canadian study found no differences in the levels of self-concept, social competence and behaviour adjustment between siblings of disabled children and typical siblings (Dyson, 1999).

A case study was carried out in New York on a sibling in her 30s with a brother who had Down's Syndrome, to determine how having a sibling with a disability had shaped her identity, experiences and life choices. The sibling felt that having a disabled brother was the primary influence in developing her identity and the reason why she was so empathetic (Flaton, 2006). Siblings affirm that having a sibling with a disability has helped them to "be more responsible, more tolerant, better see the good in others, develop a better sense of humor and be more flexible" (Burton & Parks, 1994, p. 182). The greater part of research on siblings of children with a disability suggests that the bond between a sibling and his disabled sibling is more affirming and fostering than that between typical siblings (Stoneman, 2001). Nonetheless, researchers should be vigilant as individuals who are keen to take part in studies may be more prone to providing affirmative responses than individuals who do not wish to take part (Grossman, 1972). Siblings may say that their experience of growing up with a disabled sibling was generally positive but will still highlight problems such as social isolation (Roe, 1988), adjustment difficulties (Nixon & Cummings, 1999), lower self-worth (Roe, 1988), communication problems (Magill-Evans et al., 2001) and restricted family contact (Opperman & Alant, 2003).

An American study of 49 siblings of children with disabilities found that a sibling's capacity to cope with disability was not appreciably influenced by daily pressure and managing skills; the degree of parent anxiety was a forecaster of sibling adjustment; siblings in homes with structured and steady routines demonstrated fewer adjustment difficulties and siblings adjusted more successfully in homes that exhibited excellent problem-solving skills and clear communication (Giallo & Gavidia-Payne, 2006).

When a brother or sister becomes disabled through sickness or misadventure later in life, siblings face similar challenges to those who have grown up with a child with a

disability. This can include having to be a caretaker for their sibling, having family events curbed and feeling guilty if they have a negative mind-set towards their sick or injured sibling (Joyce, 2011). One significant difference with this particular group of siblings is that they will have developed a relationship with their sibling before the ill health or accident occurred and this can be to their benefit or detriment. This group of siblings will feel the loss of their sibling, particularly if the relationship was affectionate and this sentiment can be ongoing (Joyce, 2011).

### **Sibling interactions**

Without question, having a child with a disability in the family has an influence, whether positive or negative, on the composition and operation of the family system as well as familial relationships and the roles individuals play in the family (Aksoy & Yildirim, 2008). Researchers have hypothesized that the relationship between siblings and disabled siblings is less affectionate and affirmative than typical sibling relationships. It has been suggested that siblings suppress feelings of anguish and remorse connected with having a disabled sibling and curb their own desires (Strohm, 2002). Other studies have found this to be erroneous with the relationship between siblings and disabled siblings turning out to be more affirmative than that between typical siblings (Stoneman, 2001). Factors that facilitate amicable and interactive relationships between siblings and disabled siblings include parents having an accepting attitude, the family composition, the age and gender of the siblings and the characters of the children (Aksoy & Yildirim, 2008).

When studying siblings it is important to acknowledge that there are different methodological challenges involved, especially when generalizing from small samples (Hodapp et al., 2005). Nonetheless, siblings of children with significant disabilities have

said that they delight in playing with their disabled sibling, feel tremendously faithful, engage with their sibling every day and are familiar with their sibling's activities and developmental milestones (Stoneman, 2001).

The length of time siblings choose to engage with each other can be a reliable indicator of the quality of a sibling relationship. For the most part, researchers have found that there is a high level of interaction between siblings, even when one sibling has a disability (Stoneman, 2001). School-aged siblings reported interacting with their disabled siblings in 5 activities a day lasting from 2.5-3 hours. However, this does not appear to be the case with siblings of children with Autism. Siblings were found to spend less time interacting with their sibling with Autism compared to common sibling interactions or those with siblings who had other disabilities (Knott, Lewis & Williams, 1995). Relationships were characterized by less intimacy, prosocial behaviour and nurturance than typical sibling relationships. One of the key features of Autism is a scarcity of communication and social skills and this will likely have influenced the findings of the study (Kaminsky & Dewey, 2001).

Sibling interactional roles can be asymmetrical, where one child takes the dominant role and the other child the non-dominant role. They may also be more equal where neither sibling dominates over the other (Stoneman, 2001). During childhood an older sibling characteristically dominates and the relationship is asymmetrical and this is certainly the case when the younger sibling has a disability. Conversely, older siblings with a disability are more likely to experience younger sibling dominance (Stoneman, 2001). Sibling role asymmetry is less evident when the entire family networks together and more evident when siblings with a disability are by themselves with their sibling (Costigan, Floyd & Harter, 1997). However, there is nothing to suggest that asymmetrical

interactional roles have a negative impact on either the siblings or the sibling relationship (Stoneman, 2001).

Conflict between siblings can be problematic and upsetting for parents particularly when they have a child with a disability. Researchers have studied conflict between siblings and disabled siblings resulting in diverse findings. Some have discovered that children with hyperactivity have more argumentative relationships than typical siblings (Mash & Johnson, 1983). Other researchers have found no disproportion in the intensity of conflict between disabled siblings and siblings. Moreover, siblings tease their disabled siblings to a lesser degree than children in typical sibling relationships. The changeability between study findings suggests that sibling conflict differs according to the different types of disability and siblings' personalities (Stoneman, 2001). Siblings commonly use managing rather than evading strategies when coping with family conflict and frequently take on the task of resolving difficulties (Davis & Salkin, 2005).

### **Parental influence**

How parents respond to their disabled children has an important influence on the way siblings relate to their disabled siblings (Marks, Matson & Barraza, 2005). While exploring parental influence on siblings' behaviour and attitudes Hames (2008) found that at around 2-3 years of age siblings copied their parents' behaviour towards their older disabled siblings. This included getting nappies and dummies for their disabled siblings and wiping their chins if they were dribbling. As siblings began copying their parents' behaviour they became more protective of their disabled siblings. The parents felt that the younger siblings were taking on the older sibling role and the more noticeable the disability, the sooner the caretaking began (Hames, 2008).

Parental differences in attention in families with a child with a disability may engender sibling bitterness and envy with parents tending to spend more time with a disabled sibling (Russell, Russell & Russell, 2003). Paradoxically, while siblings with a disability may receive more attention from parents, siblings do not see this as preferential treatment but more as a legitimate response to the additional caretaking needs of their disabled sibling (Stoneman, 1998).

When asked to identify specific approaches that parents could use in their interactions with a child without a disability, Powell and Ogle (1985) found that siblings of children with a disability suggested that their parents should:

- Be open and honest.
- Curb the caregiving responsibilities of siblings.
- Use respite care and other supportive services.
- Accept the disability.
- Arrange for special time with the sibling without a disability.
- Let siblings settle their own disagreements.
- Welcome other children and friends into the home.
- Encourage all siblings.
- Acknowledge that they are the most vital, most influential teachers of their children.
- Listen to siblings.
- Include all siblings in family occasions and choices.
- Encourage the sibling with a disability to do as much for himself or herself as possible.



- Recognize each child's distinctive qualities and family involvement.
- Identify different stress times for siblings and seek to diminish adverse effects.
- Use professionals when required to assist siblings.
- Teach siblings to engage with each other.
- Provide chances for a typical family life and typical family activities.
- Join sibling-related groups (Powell & Ogle, 1985).

### **Caregiving role**

Parents allocate social roles to their children, such as helping younger siblings to dress themselves. When younger siblings are asked about their care-giving role for their older non-disabled sibling many find the question silly, with the thought of helping to feed or babysit their older sibling laughable (Stoneman, 1991). Nevertheless, caring for an older disabled sibling is a routine occurrence for many younger siblings.

Researchers have found that while household responsibilities for younger siblings generally do not increase, they do experience a rise in their childcare responsibilities (Stoneman, Brody, Davis, Crapps & Malone, 1991). This is particularly valid in less prosperous households and where mothers are not well educated. When older siblings have high levels of childcare responsibility for their disabled sibling, disagreements increase and positive interactions with their disabled sibling decrease (Stoneman et al., 1991). Parents often do not listen to the worries of siblings and this results in the siblings feeling unable to communicate their needs and internalizing detrimental emotion (Strohm, 2004).

Girls, either with or without a disabled sibling generally have more home and childcare responsibilities than boys (Damiani, 1999). A study in the United States of 10 women aged between 39-53 years examined the gender structure in society that necessitates mothers and sisters, but not fathers and brothers looking after disabled children. Several women talked about struggling with the obligations placed on them and their desire to be free from the responsibility of looking after their disabled sibling (McGraw & Walker, 2007). Despite feeling this way, the women generally did not blame their brothers or fathers for not being involved in the care of their sibling, excusing them on the basis that the fathers had been busy earning a salary and the brothers were ill at ease or absent when the disabled sibling was growing up (McGraw & Walker, 2007). The researchers found that the women did not question socio-cultural rules that obligate females and not males to care for disabled members of the family. Being a good sister to their disabled sibling involved depicting the sibling as normal, playing down personal sacrifices and accommodating the gendered nature of sibling/family care (McGraw & Walker, 2007).

### **Extended family**

A study in Canada by Dyson (2010) of 11 parents of children with a learning disability aged between 8-16 years found that parents often felt unsupported by extended family members. Some relatives made it clear they believed the parents were culpable for the child's disability, others would not accept the condition and some made thoughtless comparisons with able-bodied relatives' educational successes. Additionally, parental interactions with the school system were described by all participants in the study as negative due to inept preliminary assessment of their children, labeling, disjointed service

delivery and their offspring being rebuffed (Dyson, 2010). This resulted in increased pressure and anxiety for families and left many feeling isolated from society. To overcome this many families successfully utilized personal and community resources, such as friends, in the school system (Dyson, 2010).

Siblings are in the distinctive position of being able to mediate difference between their families and the outside world because they cross between the external world with its forceful beliefs of normalcy and difference and their own family that encompasses their disabled sibling (Guite et al., 2004). This seems especially true for children with Deaf signing siblings who from pre-school age can effortlessly code-switch (change from English to Sign Language and vice versa) depending on whether they are communicating with a Deaf or hearing person.

Significantly, research has revealed that children with disabilities more commonly reside in homes with earnings below the poverty line than children who are free from disability (Fujiura & Yamaki, 2000). In America disabled children live in more impoverished circumstances than their able-bodied peers. The reason for this could be that families of children with a disability shoulder extra financial responsibilities such as increased therapy costs, specialized daycare and modification of the home environment (Parish & Cloud, 2006). Single-mother and cohabitating-partner families with children with disabilities are in even more dire financial straits (Parish, Rose, Grinstein-Weiss, Richman & Andrews, 2008). These findings suggest that the government programmes of the day are not doing enough to reduce the poverty of families with children with disabilities (Parish et al., 2008). The researchers recommend improving the plight of these families by having the government work closely with the special education community to

identify the needs of families with children with disabilities, provide greater economic support and bring about significant change.

### **Peer relationships**

When starting school, siblings are not inclined to give new friends an explanation about their older disabled sibling before the friends get to meet them. This is more likely due to the siblings' lack of understanding of disability as opposed to any social issues (Hames, 2008). However, between the ages of 7 to 11 years the siblings in Hames' (2008) study stated that they were guarded about which friends they trusted and who they would talk to about their disabled siblings. They also developed an awareness of the restrictions their disabled siblings would experience later on in life and were worried that their disabled siblings' social lives would not be the same as other adults.

While most children do not attach a negative connotation to their sibling's disability they are aware of the experience of disability, with their disabled sibling encountering external barriers and discrimination and being treated differently from themselves (Stalker & Connors, 2003). This can cause siblings distress and irritation, with some being the target of attack themselves. Many view their disabled siblings as having a range of identities and their common history as members of the same family takes priority over any diversity (Stalker & Connors, 2003).

Siblings are aware that having a disabled brother or sister makes them different. This awareness encompasses being more independent as a result of looking after themselves and their disabled sibling and making them more caring (Hames, 2008). Siblings of children with a speech impairment frequently act as interpreters for their siblings and this is deemed a form of protection from others. They also safeguard their disabled sibling from bullying

and unfavorable friends (Barr, McLeod & Daniel, 2008). Siblings can become very protective of their disabled sibling to the point that they fret about his wellbeing (Greenspan, 2001). Siblings are mindful that the experience of disability or “difference” can engender obstacles and prejudice in society and that this may have a negative impact on a disabled sibling’s feelings of self-worth (Stalker & Connors, 2003). Society views disability as abnormal and siblings often face the challenge of overcoming various limitations so that their disabled siblings can be included (Stalker & Connors, 2003). While a sibling’s view of disability is dominated by other individuals’ responses to his disabled sibling, he does not feel it is catastrophic to have a brother or sister with a disability. The experience of growing up with a disabled sibling may enhance the psychological might of siblings including developing a higher internal locus of control (Stalker & Connors, 2003).

### **Career pathways**

Siblings often choose careers in the disability field as a direct result of growing up with a disabled sibling (Chambers, 2007). However, there is no noticeable distinction between the vocational goals of siblings who have siblings with or without disabilities (Burton & Parks, 1994). Those siblings who do enter the disability field conclude that they would probably never have chosen that career path if it weren’t for the fact that they grew up with a disabled sibling (Marks et al., 2005). Caring for and supporting disabled siblings from a young age can bring about siblings following a career in the disability field, stemming from a desire to enhance the lives of those with disabilities. Siblings develop an enduring attachment thanks to their parents being down-to-earth about siblings needing to take care of each other and disabled siblings being accepted as equal members of the family (Marks et al. 2005).

In summary, when there is a child in the family with a disability sibling relationships frequently appear normal or typical. In reality, significant variables and experiences occur within the sibling and familial relationships that other families may never live through.

Key findings from the research include:

- The degree of parental anxiety is a forecaster of sibling adjustment to disability (Payne, 2006).
- Siblings view acceptance of their disabled sibling as a very important element of sibling quality of life (Moyson & Roeyers, 2011).
- Children with disabilities more commonly reside in homes with earnings below the poverty line (Fujiura et al., 2000).
- While most children do not attach a negative connotation to their sibling's disability they are aware of the experience of disability, with their disabled sibling encountering external barriers and discrimination and being treated differently from themselves (Stalker & Connors, 2003).
- The bond between a sibling and his disabled sibling is more affirming and fostering than that between typical siblings (Stoneman, 2001).
- In reality, the sibling experience is familial and not particularized (Dew, Balandin & Llewellyn, 2008).
- Siblings of children with a disability would like their parents to be open and honest, to accept their sibling's disability, encourage all siblings and provide chances for a typical family life and typical family activities (Powell & Ogle, 1985).

These findings provide important considerations for families with deaf children because there may be commonalities between the sibling groups that will offer clarity, support and encouragement to families as the years go by. The following section reviews the literature on hearing siblings of deaf children with a view to highlighting the commonalities and differences shared with siblings and siblings of children with disabilities.

## **Hearing siblings of deaf children**

### **Families with a deaf child**

In New Zealand and internationally very little has been written about the experiences of hearing siblings when there is a deaf child in the family. Researchers have tended to focus on the parental perspective rather than sibling experiences (Fillery, 2000b). Given that there is limited research generally on siblings, it is not surprising that there is insufficient information on hearing siblings of deaf children (Meadow, 1980).

When a child has a hearing loss the adjustments the family goes through are likely to be greater and more challenging (Luckner & Velaski, 2004). A hearing loss may necessitate parenting strategies to be more intricate, involving greater consideration and attention (Luterman, 1987). Parents of deaf children can have a number of matters to consider including accessing support services, dealing with financial worries and making plans they have never had to contemplate before (Luckner & Velaski, 2004).

Previous research on the experiences of hearing siblings of deaf children has tended to paint a somewhat bleak picture, however Fillery (2000a) concludes that, “The bleakness that characterises previous literature is not borne out; empathy and understanding seem to

grow with the years and efforts to share one another's 'culture' pay off in terms of deepening affection''' (p. 2). As a consequence, many professionals working with families of deaf children have begun to alter their points of view and become more aware of families' internal strengths and employment of external resources (Luckner & Velaski, 2004).

A United Kingdom study by Tattersall & Young, (2003) involving 6 hearing siblings aged between 18-60 years found that when participants spoke about their experiences of growing up with a deaf sibling there were simultaneous versions of reality within individual narratives. At first, siblings described their experiences of growing up with a deaf sibling as normal but as the interviews progressed and upon further reflection siblings began to view their experiences as rather unique. Any inconsistency in the narrations was attributed to participants trying to explain and make sense of their experiences (Tattersall & Young, 2003). It is not uncommon for research participants to re-interpret or reconstruct past experiences (Gregory, Bishop & Sheldon, 1995). Earlier difficulties that participants initially considered noteworthy can in the fullness of time appear unimportant. Additionally, successive happenings can revise the participants' view of former happenings. This isn't due to untruthfulness but rather that recollections can alter over time and give another slant to a narrative (Gregory et al., 1995).

### **The family and ecological systems approach**

One of the first documented reports of a hearing sibling interpreting for their deaf sibling was in 1636 in a town called Vilsholven along the River Danube. Keynes (1966) noted:



His Excellency . . . spied a poore Boy standing among other poore people begging for reliefe, who looked very strangely and could neither speake nore heare, but a little at his mouth and nose, having neither eares nore passage to heare with, and his face very thin and drawne aside, yet when one hallowed hee heard and answered againe with a noise; there was with him his sister, a pretty girle, who when one spake to him, made him understand by signes (p. 239).

It would appear from this vignette that the deaf/hearing sibling relationship is particularly close and entails a special understanding (Gregory, 1995). Nevertheless, due to the scarcity of research on hearing siblings' experiences the overall picture of the positive and negative effects still remains unclear. A handful of studies have been published on hearing siblings of deaf children and the field would be vastly enhanced by further enquiries into the contribution that hearing siblings make to the family system (Bat-Chava & Martin, 2002). It is unknown whether hearing siblings view their deaf siblings as having unique attributes as opposed to having an impairment or disability and what impact a hearing sibling's acceptance or rejection of his deaf sibling has on the family system. In addition, it has yet to be established whether conflict commonly occurs in deaf and hearing sibling relationships.

The family is a very powerful system and encompasses family relationships that are co-dependent and reciprocally interactive. Modification in one area of the family system significantly affects all other areas of the system (Minuchin, 1974). Children's normal and abnormal development according to Mash and Wolfe (2005) relies on a range of social and ecological situations, including the child's family and cohort system and the larger social and cultural milieu. The way in which a family copes with usual and unusual stresses

plays a significant part in children's ability to adjust to and accept change. It is not known whether there are specific factors that assist hearing siblings in developing resilience.

Urie Bronfenbrenner's bio-ecological model of human development was first introduced in the 1970s and continued to be refined up until the mid 1990s. Bronfenbrenner's (1995) bio-ecological model of human development suggests that the child and family comprise a system that is influenced by interactions between individuals and the natural world over time. The ecological model's five socially organized subsystems help sustain and direct human development. They extend from the microsystem, which relates to the connection between a growing person and his direct environment such as family and school, to the macrosystem, which relates to institutional configurations of culture such as the financial systems, traditions and quantity of learning (Bronfenbrenner, 1995).

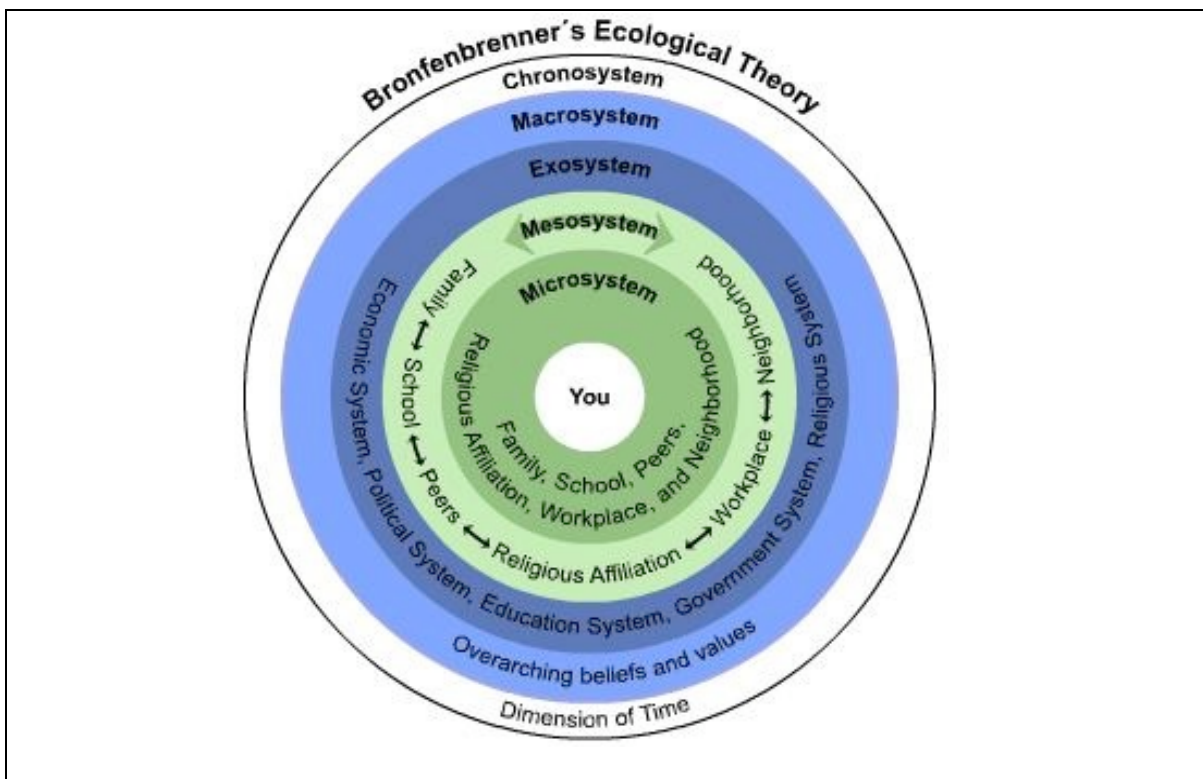


Figure 1. Bronfenbrenner's (1995) Ecological Model of Human Development.

Bat-Chava & Martin, 2002 suggest that “because hearing brothers and sisters are the first peers of deaf children and important actors in their families, understanding the social development of deaf children requires we examine the relationships between them and their siblings” (p. 74). In recent years researchers have become uneasy about studies that focus primarily on pathology and supposedly ‘unhealthy’ families and this has resulted in a shift towards reporting on families’ intrinsic power and use of external support systems (Luckner & Velaski, 2004). Studies have found that families who have a child with a disability are as secure as other families. With a deaf child in the family, family members develop increased resiliency, improved communication capabilities, compassion and acceptance (Salisbury, 1987). Researchers note that a range of professionals such as audiologists and intervention teachers come into the family’s life and offer facts and suggestions that sometimes unintentionally weaken the parents’ influence (Luterman, 1987). As a result parents and siblings often become forceful advocates for the deaf child (Mindel & Feldman, 1987).

## **Communication**

Individuals may not be able to choose their siblings but they can decide how, when and why they communicate with their siblings (Rocca, Martin & Dunleavy, 2010). The gender of siblings, their age disparity and whether the family is a nuclear family affects the interactions of adult siblings. Where a child has only one sibling communication between siblings is used more for management. Where there is more than one sibling in the family communication is used more for enjoyment and leisure (Rocca et al., 2010).

Approximately 91.5% of children with a hearing loss are born to families in which all other members are hearing (Gallaudet Research Institute, 2001). In families where

there is no previous experience of deafness this can be overwhelming, cause a family crisis and crumble/destablize family structures (Bat-Chava & Martin, 2002). Parents can be anxious about how their child will function in the normal world, how their family and friends will respond and what the experience of having a deaf child will do to the remainder of the family (Koester & Meadow-Orlans, 1990). The difficulties that a deaf child experiences in developing communication can be of significant concern when language milestones are not reached naturally and comparably to hearing children. If parents decide that they would like their deaf child to communicate verbally then these skills have to be explicitly taught (Koester & Meadow-Orlans, 1990) compared to the more naturalistic and incidental learning of language experienced by hearing children. Family and sibling interactions are not always smooth due to family members not sharing the same communication mode as a deaf child. If a child's main method of communication is sign language then the effectiveness of the family's interactions will be determined by how at ease and experienced each family member is in using sign (Henderson & Hendershott, 1991). Acting as an interpreter for other family members places additional responsibility on a hearing sibling and can engender feelings of frustration when interpreting for family members impedes the hearing sibling's own social interactions (Fillery, 2000b).

Exchanges with family members are normally enhanced when a deaf child has at least one parent with a hearing loss or when parents frequently mingle with deaf adults. Parents who have regular contact with deaf adults show improved interaction awareness compared to parents who have no contact with deaf adults (Hintermair, 2000).

## **Relationships with siblings**

The contextual and individual composition of a child's family affects deaf/hearing sibling relationships. This includes: (a) the characteristics of each of the siblings (i.e., age, gender and birth order of each child), (b) the characteristics of the family in which the children live (i.e., family size and ethnicity) and (c) parenting, (child-rearing practices used by the parents), (Stoneman & Brody, 1993).

Hearing siblings when talking about their relationship with their deaf sibling describe their connection as “normal” involving the sharing of common interests and archetypal sibling arguments (Tattersall & Young, 2003). Temperament is a crucial determinant in how well hearing siblings adjust to having a deaf sibling. Older hearing siblings with a positive disposition appear to adapt more easily to having a deaf sibling and form warm relationships more easily. Conversely, older siblings with irritable dispositions find it harder to adapt and lack persistence in forming a relationship with their deaf sibling (Raghuraman, 2008). It is yet to be determined whether hearing siblings feel that having a deaf sibling has shaped their identity, experiences and life choices.

Adolescence can be a complicated period for young people and it appears that hearing siblings of deaf children are no exception. During the teenage years hearing siblings can feel self-conscious about being with their deaf sibling in the presence of their peer group (Raghuraman, 2008). It is uncertain whether at different stages of life the hearing and deaf sibling relationship changes.

There are commonalities between sibling relationships of deaf children and sibling relationships of children with other disabilities. Irrespective of the disability it seems that there are generally more positive outcomes for siblings from large families (Bat-Chava & Martin, 2002). This despite the fact that parents in large families tend to have less time to

spend with each child, with the care of a deaf child taking time away from other family members. Positive outcomes are attributed to parents using strategies that promote effective sibling relationships, such as minimizing the differences between siblings and thorny issues being openly dealt with (Bat-Chava & Martin, 2002). It is unknown whether the presence of a disability engenders sibling rivalry or whether sibling relationships are generally positive, nurturing and equitable.

### **Relationships with parents**

Parenting approaches that treat hearing/deaf siblings differently can lead to sibling rivalry and hearing siblings feeling that the parents favour the deaf child (Luterman, 1996). Hearing siblings may feel envious and overlooked as a result of parental and professional attention being directed towards their deaf sibling (Marschark, 1997). Hearing siblings may feel that their parents favour their deaf sibling or that they have greater expectations of the hearing sibling (Atkins, 1987).

It is not categorically known from the hearing siblings' perspective whether they experience parental differential attention when there is a deaf child in the family and whether they believe that their needs are adequately and equitably met. However, when parents make pessimistic comparisons between their hearing and deaf children by highlighting the capabilities of the hearing sibling this can negatively affect the relationship of the deaf and hearing siblings (Bat-Chava & Martin, 2002). When parents feel "powerless" the parent-child relationship as well as the hearing child's development and academic achievement are likely to be compromised (Pollard et al., 1999). A German study involving 317 parents of deaf children found that parents who often interacted with other parents of deaf children and with deaf adults developed loving, accommodating and

unquestioning relationships with their deaf children (Hintermair, 2000). Parents consistently navigate decisions and trade-offs to ensure that all of their children feel their needs are equitably met (Evans, 1998).

### **Caregiving role**

The diverse role of hearing siblings can be catalogued as playfellow, buddy, guardian, assistant, rival and parent surrogate (Atkins, 1987). Hearing siblings are aware that the relationship they have with their deaf sibling is somewhat unique in terms of the level of responsibility they may be given for their sibling. Some parents of deaf children intentionally limit the number of tasks they give to older siblings because they do not want them to feel overloaded, or parents will give older siblings tasks that they appreciate so they feel a valued part of the family (Atkins, 1987).

Older sisters by and large take on caring for their deaf sibling with intermittently unfavorable affects, while older brothers are less affected because society does not assign them the role of caregiver (Luterman, 1996). Younger siblings are more likely to seek assistance and protection from an older sister than an older brother as older sisters characteristically extend more encouragement, kindness, closeness and collaboration to a younger sibling than older brothers (Buhrmester & Furman, 1990; McHale, Sloan and Simeonsson, 1986). While older sisters tend to have more childcare responsibilities with their deaf sibling than older brothers due to their mother's greater workload and engagement with their deaf sibling, parental acceptance of the sibling's hearing loss and candid communication with the hearing sibling can act as mediating influences. Older sisters of children with a hearing loss are more autonomous in self-care responsibilities than older sisters of hearing children (Schwirian, 1976).

Sixty-two percent of hearing siblings feel some sense of responsibility for their deaf siblings (Gregory, Bishop & Sheldon, 1995). Older siblings feel more accountable for their younger deaf siblings in social settings than siblings who do not have a brother or sister with a hearing loss (Atkins, 1982). The role of a hearing sibling is one of “go-between” where the sibling takes on a level of responsibility that may leave him feeling angry and resentful when the role impedes his social life. Additionally, hearing siblings who act as a go-between may lack a sense of identity and feel deprived of their childhood (Fillery, 2000b).

However, a hearing sibling’s experience of having a deaf child in the family is not necessarily negative. Older siblings of deaf children go through a range of positive and negative feelings similar to those of older siblings of typical children (Raghuraman, 2008). It is yet to be determined at what stage hearing siblings develop an understanding of their deaf sibling’s hearing loss and whether parents take a proactive role in sharing information or whether an understanding develops spontaneously over time. In addition, whether the experience of hearing siblings of deaf children influences aspects of their lives such as career pathways.

### **Relationships with peers**

Hearing siblings can be very protective of their deaf siblings. Siblings might not want their friends to meet their disabled sibling because they are worried that their brother or sister will be treated inequitably (McHale, Sloan & Simeonsson, 1986). Furthermore, siblings may have to handle people’s reactions to their disabled sibling in a range of settings, including mainstream classrooms, school recreational areas and in their neighborhood (McHale et al., 1986). While some hearing siblings report that they have



never experienced any negativity towards their deaf sibling in the hearing world, others share personal accounts of their deaf siblings being scoffed at by individuals, or their deaf sibling being prevented from entering the local cinema because he was deaf (Tattersall & Young, 2003). The emotional impact that hearing siblings might experience from society's or the extended family's positive/negative treatment of their deaf sibling is uncertain.

### **Extended family and the Deaf community**

Being able to share their worries with other family members such as grandparents is a crucial resource for hearing siblings (Luterman, 1996). Hearing grandparents provide their hearing children and deaf grandchildren with varied and valuable support (Nybo, Scherman & Freeman, 1998). Parents feel it is important to receive support from their immediate family, extended family, community and professionals (Meadow-Orlans, Mertens & Sass-Lehrer, 2003).

A German study involving 317 parents of deaf children found that parents who often interacted with other parents of deaf children and with deaf adults developed loving, accommodating and unquestioning relationships with their deaf children (Hintermair, 2000). Hearing siblings' lives are enriched by learning sign language, meeting other deaf people and interacting with the Deaf community (Ladd, 1988). Hearing siblings also tend to be more tolerant of difference, are empathetic and mature (Luterman, 1987). The kinds of interactions hearing siblings and their families engage in with the Deaf community and find valuable are yet to be determined.

## **Society's cognizance of disability and hearing loss**

The social model of disability describes an obvious division between impairment – an individual's functional loss or limitation – and disability, caused by barriers imposed by environmental or policy interventions (Oliver, 1990; Barnes, 1991). “Attitude” is a concept that is problematical to measure (Marini, 2012). Generally, it is only when attitude surveys are anonymous that researchers receive candid responses, otherwise respondents are inclined to provide answers that are socially pleasing. To do otherwise is deemed socially unacceptable (Anotak & Livneh, 1988).

Attitude is comprised of three components, namely cognitive, affective and behavioural (Eagly, Mladinic & Otto, 1994). The cognitive component encompasses our thoughts and beliefs, the affective our feelings or emotions when we think about a person, object or event, and the behavioural which induces us to act in a certain way (Eagly et al., 1994). It is worth noting that individuals are not uniformly reliable in the three components that shape attitudes. In circumstances where people are feeling powerless, for example where an employee does not like his employer, he can pretend to like the person thus behaving in a way that is socially acceptable as well as enabling him to secure a raise or avoid being fired! (Marini, 2012).

Harold Yuker in his 1988 book *Attitudes Toward Persons with Disabilities* suggests that researchers have an intentional or unintentional negative bias in forming and deciphering attitude survey results by making the disability the most significant facet of the survey while disregarding alternative facets that social psychologists have demonstrated affect individuals' attitudes. These facets include physical attractiveness, competence and social skills (Marini, 2012). Researchers have rigorously debated the notion of being able to effectively measure societal attitudes towards disability and have concluded with all of

its complexities it is impossible to make generalizations about society as a whole (Marini, 2012).

Notwithstanding, there is an overabundance of empirical and anecdotal studies that support the view that attitudes towards individuals with disability are predisposed to being negative (Marini, 2012). In various studies researchers have highlighted many of the stereotypical attitudes directed towards people with disabilities. These include individuals with disabilities being perceived as eternally child-like (which aligns with the medical model paradigm), as objects of pity or victims, a danger to society, ailing and inept, unable to make a valuable contribution and a psychological and financial load on society (Mackelprang & Salsgiver, 2009).

There are numerous reasons why some individuals have a negative attitude towards people with disabilities. These are: disability being viewed as a punishment for a person's sins; when growing up able-bodied people not having opportunities to interact with disabled people; socio-cultural conditioning where society tends to revere the "body beautiful"; being afraid of becoming disabled themselves and the media reinforcing negative stereotypes (Livneh, 1991).

Pity and admiration are sentiments frequently expressed towards people with disabilities (Zola, 1991). One might suppose that hearing or reading uplifting stories would enhance the growth of positive attitudes towards those with disabilities, however this is simply not the case. Such stories can send a double message, that people with disabilities can accomplish great feats and others with disabilities who are not as successful do not achieve because they are feeble or lack impetus (Zola, 1991).

Family resilience is the conduit to navigating change with equanimity. When disability comes into the family it throws the family system into disarray, but just for a

limited time. In due course the family system reinvents itself, adapting to the “new normal” and it is family resilience that enables this to happen (Marini, 2012). The characteristics of family resilience are preserving control, individuality and the soundness of boundaries (Antonovsky, 1987). Resilient families convert hazards into contests, unpleasant experiences into learning opportunities and unyielding public attitudes into accommodating attitudes (Antonovsky, 1987). They achieve this by having candid and vigorous communication within the family, developing strong relationships with service and resource people, setting objectives and troubleshooting difficulties, putting in place disaster management tactics and being constructive, confident self-advocates (Antonovsky, 1987).

In order to enhance society’s attitudes towards people with disabilities there should be more interaction with, and awareness of, people with disabilities; accurate education and facts should be made available to reduce false impressions regarding disability and a disabled person should be the one imparting the education (Marini, 2012). Non-disabled and disabled individuals meeting in settings where there is common interest and equity has helped society’s attitude to be more positive towards disability. Even so, many people with disabilities consider that there is still significant room for improvement (Marini, 2012).

Hearing siblings have to manage society’s reactions to their deaf sibling in a range of settings, including mainstream classrooms, school playgrounds and in their local neighbourhood (McHale et al., 1986). Hearing siblings have shared anecdotes about their deaf siblings being ridiculed by the public and even being prevented from entering public arenas (Tattersall & Young, 2003).

## **New Zealand's deaf and hearing impaired population**

In New Zealand there is limited research concerning the deaf and hearing impaired. In fact there has previously been no one project aimed solely at defining the hearing impaired and deaf populations of New Zealand (Greville, 2005). The New Zealand census of 1991/92 reported that over 90,000 more males than females suffer from a hearing loss with a significant link of hearing loss to age. The census of 2006 noted that a total of 24,090 people had the ability to use NZSL, New Zealand's third official language. A total of 6,057 reported that they were able to communicate in all three languages, English, NZSL and Maori (Statistics New Zealand, 2006).

A 2001/02 New Zealand disability study of children under 15 years showed that boys are more likely than girls to have a hearing disability (Greville, 2005). The prevalence of hearing loss among Maori in the younger age group is considerably higher than among non-Maori. Adult Maori are half as likely to use hearing aids or assistive devices as non-Maori. Just 9% of children with a hearing loss use hearing aids and affordability is the most common reason for this (Greville, 2005). Individuals (both adults and children) with a hearing loss are the least likely disability group to be given a disability allowance or an invalid's benefit. The same study showed that an estimated 6,900 people use New Zealand Sign Language and 51,000 people with a hearing loss can lip-read (Greville, 2005).

In past years some mainstream teachers' attitudes towards working with deaf children have been unhelpful and biased. A study by Panda and Bartel (1972) found that mainstream teachers when given the choice, preferred to work with children with intellectual disabilities rather than children who were deaf or blind. They concluded that without equal opportunity laws and technology being available, deaf and blind children must have been significantly marginalized during this time. In 1993 New Zealand ratified

the United Nations Convention on the Rights of the Child (UNCROC). Two of the general principles underpinning the Convention were that all children have the right to protection from discrimination on any grounds and the best interests of the child should be the primary consideration in all matters affecting the child.

As recently as 1996 when researchers evaluated 28 surveys canvassing the views of 10,000 mainstream teachers regarding inclusion, they discovered that while more than two-thirds of the teachers agreed with inclusion in principle, less than one third believed that disabled children would benefit from inclusion. Teachers felt that children with severe disabilities would have a detrimental affect on mainstream students (Scruggs & Mastropieri, 1996).

In New Zealand, the majority of deaf children in mainstream learning environments receive support from Resource Teachers of the Deaf and Advisers on Deaf Children. RTDs are employed by either of the two Deaf Education Centres and work with deaf children in pre-school to high school learning environments. RTDs provide support in one-to-one situations or in the pre-school or classroom, supporting deaf children in accessing the national curriculum. They consult closely with parents, mainstream teachers, AODCs and other professionals connected with the deaf child. Luckner (2006) noted, an itinerant teacher (RTD) can be described as:

“a professional who provides instruction and consultation for students who are deaf or hard of hearing and most generally travels from school to school” (p. 24).

Advisers on Deaf Children are employed by the Ministry of Education and work directly with parents, caregivers and head teachers to help deaf children and young deaf people with their hearing requirements. AODCs work with deaf children who are referred

to the Ministry of Education by health professionals. Support can be provided in the child's home, early childhood centre or school (Ministry of Education, 2012).

Professionals who work with deaf or hearing-impaired children have traditionally been the decision makers, in meetings where parents have been given few opportunities for conversation or collaboration (Meadow-Orlans & Sass-Lehrer, 1995). However, when families, teachers and professionals include siblings in educational and support-services, brothers and sisters become a significant component of family centred practices (McBride, Brotherson, Joanning, Widdon & Demmitt, 1993). Deaf children require thoughtful, well-informed and accomplished professionals who advocate for deaf children and help them to achieve great things (Luckner & Ayantoye, 2013). A deaf child should, first and foremost, be viewed as a child and secondly as a child with complex needs (Atkins, 1987). Effective parent, sibling and family focused support would involve the family bringing its own to-do list to the meeting and having the opportunity to identify issues, concerns and questions (Meadow-Orlans & Sass-Lehrer, 1995).

Sibling relationships are the only relationships that last a lifetime (Schulman, 1999). During that period hearing siblings go through contradictory experiences growing up with a deaf sibling (Tattersall & Young, 2003). On the one hand hearing siblings describe the typical childhood they had, where communication was effortless and there was complete acceptance of their deaf sibling. On the other hand they describe how life was unique for them with additional responsibilities, feeling dissimilar to their friends and the challenges of communicating with their deaf sibling. These complementary realities need to be examined together in order to comprehend the intricacy of hearing siblings' experiences (Tattersall & Young, 2003).

These findings provide a measure of insight into the experiences of hearing siblings when there is a deaf child in the family, while at the same time underscoring that there is plentiful information still to be discovered about hearing and deaf sibling relationships.

The key findings are:

- Bronfenbrenner's (1995) bio-ecological model of human development suggests that the child and family comprise a system that is influenced by interactions between individuals and the natural world over time.
- In recent years researchers have become uneasy about studies that focus primarily on pathology and supposedly 'unhealthy' families and this has resulted in a shift towards reporting on families' intrinsic power and use of external support systems (Luckner & Velaski, 2004).
- By and large, the experiences of hearing siblings growing up with a deaf sibling appear to be divergent. On the one hand hearing siblings take on more responsibility within the home, feel dissimilar to their deaf siblings and believe that they will never have any meaningful communication with their deaf sibling. On the other hand hearing siblings believe that they are no different from their peers, that communication has been achieved with their deaf siblings with relative ease and deafness has been forgotten in a culture of acceptance (Tattersall & Young, 2003).
- Hearing siblings when talking about their relationship with their deaf sibling describe their connection as "normal" involving the sharing of common interests and sibling arguments (Tattersall & Young, 2003).



- With a deaf child in the family, family members develop increased resiliency, improved communication capabilities, compassion and acceptance (Salisbury, 1987).
- Older sisters by and large take on caring for their deaf sibling with intermittently unfavorable affects, while older brothers are less affected because society does not assign them the role of caregiver (Luterman, 1996).
- A 2001/02 New Zealand disability study of children under 15 years showed that boys are more likely than girls to have a hearing disability. The prevalence of hearing loss among Maori in the younger age group is considerably higher than among non-Maori (Greville, 2005)
- When researchers evaluated 28 surveys canvassing the views of 10,000 mainstream teachers regarding inclusion, they discovered that while more than two-thirds of the teachers agreed with inclusion in principle, less than one third believed that disabled children would benefit from inclusion (Scruggs et al., 1996).
- Hearing siblings' lives are enriched by learning sign language, meeting other deaf people and interacting with the Deaf community (Ladd, 1988).
- Siblings perform a vital role in families and researchers should explore in greater detail the contributions that hearing siblings of deaf children make to the family system (Minuchin, 1974).
- Sibling relationships do not form in seclusion but within multifaceted family relationships. Support services should therefore be accessible to both hearing

and deaf siblings and their parents (Antonopoulou, K., Hadjikakou, K., Stampoltzis, A. & Nicolaou, N., 2012).

- There is an overabundance of empirical and anecdotal studies that support the view that attitudes towards individuals with disability are predisposed to being negative (Marini, 2012).
- Resilient families convert hazards into contests, unpleasant experiences into learning opportunities and unyielding public attitudes into accommodating attitudes (Antonovsky, 1987).
- In New Zealand, RTDs and AODCs support deaf children in pre-school to high school education settings.
- Hearing siblings go through contradictory experiences growing up with a deaf sibling. Understanding the complementary realities and how they intertwine together is the key to fully understanding the experiences of hearing siblings (Tattersall & Young, 2003).
- Effective parent, sibling and family focused support should involve the family bringing its own to-do list to a meeting and having the opportunity to identify issues, concerns and questions (Meadow-Orlans & Sass-Lehrer, 1995).

The review of the literature has exposed the need for research on hearing siblings of deaf children. To further contribute to this body of knowledge this study has been undertaken to address these research questions –

- What are the experiences of hearing siblings when there is a deaf child in the family?

- What are the knowledge and perspectives of Teachers of the Deaf/Advisers on Deaf Children about the influence on hearing siblings of having a deaf sibling?

The findings from this study will be used to compare and expand upon what has been previously found with regard to siblings, siblings of siblings with a disability and siblings of siblings who are deaf. The following chapter outlines the methodology employed to address the research questions of what are the experiences of hearing siblings when there is a deaf child in the family and what are the knowledge and perspectives of professionals working in the field of deaf education in New Zealand?

## **Chapter 3**

### **Method**

#### **Introduction**

This chapter describes the study's qualitative, quantitative, mixed methods research design and outlines the approach that was followed. Information is provided about the enlistment of participants, ethical considerations intended to preserve the anonymity of participants, the use of interviews and surveys for data collection and the analytical methods employed in the study. The first part of the study involved face-to-face interviews to determine the experiences of hearing siblings when there is a deaf child in the family and to comprehend the influence those experiences had on the hearing siblings' lives. Data collected from this first stage formed the basis for a questionnaire for Resource Teachers of the Deaf ("RTD") and Advisers on Deaf Children ("AODC") and was the second stage of the study. The objective of academic researchers is to construct information that links with that of colleagues in such a manner that it enables all facets to ultimately be validated, copied and extended further (Franklin, 2013).

This study utilized a mixed methods research design. Mixed method designs are commonly used when one method may not expansively answer the research question (Richards, 2009). Bergman (2010) suggests that mixed methods research is suitable for examining how meaning is formed and for developing knowledge of the way in which participants "make sense of their experiences or report on attitudes in interviews or questionnaires" (p. 172). There are four recognized outcomes of collecting data using the qualitative and quantitative approaches. These outcomes are corroboration, elaboration, complementarity and contradiction, with each phase describing the varied aims and means

of evaluating and connecting information (Brannen, 2005). When utilizing the mixed method approach equal weighting is not given to both components during analysis of the data (Morse, Wolfe and Niehaus, in press). One component provides the analytic core and the other component's findings add to or provide further explanation to the findings of the core component (Morse et al., in press). This research project is a qualitatively driven project, with a qualitative core and a quantitative sequential component (Richards & Morse, 2007). The researcher elected primarily to undertake a qualitative study, with the qualitative component being the means of identifying the findings. The sequential component, the quantitative method, asks the same questions of all participants and involves an equivalent sample size with questions contained in a survey (Richards & Morse, 2007). The advantage of using mixed methods research is its capacity to produce a workable middle point drawn from various perspectives utilising the strengths of both qualitative and quantitative research to answer the research question (Onwuegbuzie & Turner, 2007).

Triangulation refers to the collection of different perspectives on the same question or topic (Richards & Morse, 2007). Triangulation is used within the mixed methods research design with convergent validity being established from both qualitative and quantitative positions (Watson, McKenna, Cowman & Keady, 2008). It involves judicious research designs to make certain an identical question is focused on and satisfied by each of the intended approaches (Richards & Morse, 2007). The term *triangulation*, likening it to a surveyor making sightings from two known points to a third was conceived by Goffman (1989).

## **Qualitative Methodology**

A qualitative methodology was considered the best approach to follow in answering the research question “What are the experiences of hearing siblings when there is a deaf child in the family?” The inherent strength of qualitative methodology is that it clarifies how the “macro” (social class position, gender, locality) is deciphered into the “micro” (i.e., everyday practices, understandings and interactions) that direct individual behavior and generally affords a broader interpretation (Barbour, 2008). Qualitative methodology answers the research question by effectively unearthing and recording material in the participants’ own words, mirroring their individual viewpoint, beliefs, ideals, outlook and the actual data about their lives (Saldana, 2011). Understanding a phenomenon from the point of view of the participant and his particular social and institutional context is largely lost when textual data is quantified (Kaplan & Maxwell, 1994). Researchers who work with qualitative data are for the most part trying to gain fresh information as opposed to something that is presently known (Richards, 2009). Qualitative methodology entails a researcher explaining the topographies of participants and the events of a study without relating events by way of measurements or amounts (Thomas, 2003).

A researcher who is unaware of the purpose of his inquiry or has no idea of the outcome being aimed at can expect to have significant practical and ethical difficulties arise. Knowing the desired outcome for the research guides the research design (Richards, 2009). When designing a qualitative research project a researcher should bear in mind three specific questions. What are you asking? How are you asking it? What data will you need to provide a good answer (Richards, 2009)? The advantage of qualitative methodology is that it enables the researcher to work from within a naturalistic paradigm

that is grounded in the belief that people's interpretations of real life experiences provide the key to better understanding of particular aspects of an experience or phenomenon (Neuman, 2000). One of the key strengths of qualitative methodology is that it is adaptable with the ability to alter the research design as the researcher gains knowledge from the data (Richards, 2009). Qualitative research has however been censured for its lack of objectivity and validity error (Paley, 2005).

In this mixed methods study the researcher used grounded theory whereby common themes were identified and used to develop a theory (Neuman, 2000). This is an inductive approach developed by Glaser and Strauss (1967) in which theory is generated from a process of data collection, coding and analysis. Shipman (1997) explains, "the data guides the development of theory and in turn, the latter guides the next phase of data collection" (p. 60). This methodology prevents researchers from trying to force data to fit a preconceived theory (Glaser et al., 1967). Instead grounded theory encourages the generation of valid and meaningful theories that fit and work, firstly, because their concepts and categories are appropriate and relevant, and secondly, because they are able to both explain, and predict, the phenomena under study (Blaikie, 1995). A grounded theory inquiry usually commences with a question like "What is happening here?" This type of inquiry meets the researcher's desire to learn from participants and understand a process or situation that constantly changes or evolves over time. Through comprehensive examination the researcher builds theory grounded in data (Richards & Morse, 2007). The order in which this research was conducted is noteworthy because the qualitative data was collected first and then the theories generated from the qualitative data formed the quantitative component of the research.

In determining the experiences of hearing siblings when there is a deaf child in the family the researcher utilised Bronfenbrenner's (1995) bioecological model of human development. This model involves the exploration of interactions, or proximal processes that occur over time between people and their environment. Bronfenbrenner's (1979) paradigm, which is the key to an individual's development, identifies four systems including the microsystem or immediate environment (i.e., an individual's family or whanau), the mesosystem (other microsystems that interact either with the person or others in his or her immediate environment, i.e., school), the exosystem or wider environment (social settings that do not include the individual but which still impact on his or her life, (i.e., a school's board of trustees) and the macrosystem, which incorporates the wider cultural context (such as values, customs, laws and resources of a specific culture). Bronfenbrenner's (1979) systems perspective was also used as a foundation for the researcher's discussion of the findings.

## **Quantitative Methodology**

Quantitative methodology entails a researcher concentrating on measurements and amounts (more and less, larger and smaller, often and seldom, similar and different) of the topographies presented by the participants and events in the study (Thomas, 2003). Within the health science field quantitative research is employed to carry out interventions, manipulate variables and explore the contrasts between topics and groups (Polit, Beck & Hungler, 2001). Quantitative research designs commonly include experimental, quasi-experimental, between or within subjects, cross-sectional or longitudinal, retrospective or prospective processes (Polit et al, 2001). Quantitative data on its own does not assist



advancement either in the physical sciences or education (Niaz, 2008). Rather, it is mixed methods research in education that engenders the building of robust strategies as long as the problem situation decides the methodology (Polit et al, 2001). However neither qualitative nor quantitative research is more beneficial than the other (King, Keohane & Verba, 1994).

Surveys or questionnaires sit within the quantitative methodology framework and were utilized during this study. Both are considered effective tools for corroborating the viewpoints of qualitative research participants (Parahoo, 1997). Framing questions around qualitative data that has already been collected as part of a study is an accepted practice in sequential mixed methods research (Watson et al., 2008).

## **Mixed Methods Research**

The theory that forms the foundation for a research project is known as a paradigm. The function of a paradigm is to illuminate the purpose and aspirations of the research project and to guide the way in which information is revealed and implications are shaped (MacKenzie & Knipe, 2006). Pragmatism is a paradigm that has been recognized as making a valid contribution to social science research (Teddlie & Tashakkori, 2009). According to Pansiri (2005) pragmatism values both the objective and subjective stances and acknowledges that “both reality and social reality are based on beliefs and habits socially constructed” (p. 197). This universal view of pragmatism has prompted the development of mixed method designs that acknowledge the importance of historical and social factors and multiple methods of data collection (Evans, Coon & Ume, 2011). Information gained from the pragmatic perspective is diverse with an alignment to

actuality, attention to remedying issues, and contemplation of results of actions (Cresswell, 2003). Although mixed methods research does not strictly have a clear philosophical basis, pragmatism is generally understood to be its core structure (MacKenzie & Knipe, 2006). As such it is an appropriate paradigm to employ in determining the experiences of hearing siblings when there is a deaf child in the family. Research that employs mixed methods increases the likelihood of correctly encapsulating the core of the phenomena being examined and thus ensuring a more holistic point of view (Adami & Kiger, 2005).

## **Participants**

The researcher initially had informal discussions with her colleagues and members of the Deaf community in an effort to identify a cohort of hearing siblings of deaf adults living in the South Island. Following these discussions six hearing siblings of deaf adults, four women and two men aged between 18 and 65 years, residing in the South Island were recruited to take part in the study. The researcher personally knew one of the hearing siblings involved in the study. Contact was made by way of Resource Teachers of the Deaf, an open invitation to take part in the study being extended through Deaf community groups and the Sign Language Interpreters Association of New Zealand. Participants in the study were required to meet the following criteria:

- Be aged between 18 and 65 years.
- Have a deaf sibling who was 16 years or older.
- Reside in the South Island.
- Be available to take part in an interview lasting 60-90 minutes.

- Be willing to review the typed transcripts of their interviews and provide the researcher with feedback/amendments concerning the transcripts.

The six participants who agreed to be in the study were asked to choose a pseudonym for themselves. Once the pseudonyms were selected the group comprised of:

- Chloe, a female in her 60s whose younger brother lost his hearing later in life. Chloe's brother's hearing loss was identified as being hereditary.
- Chris, a male in his 30s whose younger sister communicated in NZSL. Chris's sister's hearing loss was attributed to their mother contracting Rubella while she was pregnant.
- Kelly, a female in her 20s with a younger brother with a cochlear implant. Kelly's brother was born profoundly deaf, but no cause was identified for his hearing loss.
- Penelope, a female in her 30s who had several older deaf siblings who were all NZSL users. Penelope's sister was believed to have lost her hearing as a result of her sister's mother contracting Rubella while she was pregnant.
- Ani, a female in her 30s who had a young brother who was an NZSL user with additional needs. The reason for Ani's brother's hearing loss was never identified.
- John, a male in his 20s with a younger brother with a cochlear implant. John's brother contracted Meningitis when he was 2 years' old and lost his hearing as a result.

## **Ethics**

The University of Canterbury's Human Ethics Committee approved the study. An information letter and consent form approved by the Committee was sent to each of the participants in the study explaining what their contribution would involve (Appendix 1 and 2). Participants were advised that every attempt would be made for their identities to remain confidential and that they could elect to withdraw from the study at any point up until final analysis and presentation of the data. The information letter also advised the participants that if the researcher knew any of them personally, their involvement would attract no personal penalty or benefit. Participants were also assured that any data relating to the study would be stored securely at the University of Canterbury.

## **Interviews**

A researcher should recognize the values, assumptions and beliefs that he brings to the interview process (Cresswell, 2003). A researcher's prior knowledge, experience, training and perspective can influence the way data is collected, analysed and interpreted (Patton, 2002). Before beginning the interview process the researcher reflected on and acknowledged some of the assumptions or biases she had around the research topic and noted these in her PhD log.

The semi-structured interview is the most common form of interview used by researchers in which the researcher brings a predetermined line of questioning to the interview (Franklin, 2013). Six hearing siblings took part in semi-structured, face-to-face interviews. The interview questions were trialed with one participant in order to field test them, make adjustments, and receive feedback. A revised set of interview questions was

then used with subsequent participants. The participants were offered the option of being interviewed in their own homes or at the researcher's home. Three hearing siblings chose to be interviewed in their own homes and three chose to be interviewed in the researcher's home. The interviews lasted between 60-90 minutes and were recorded using a Digital Voice Recorder.

The researcher used Bronfenbrenner's (1979) paradigm as a frame for both the interview questions and surveys (Appendix 3 and 4). As part of Bronfenbrenner's (1979) microsystem participants were asked about their family and the immediate environment in which they lived. With the mesosystem participants were asked about the connection between their home and school. The exosystem examined environments in which the participants were not involved and the macrosystem involved questions around the larger cultural context. Once the interviews were completed the researcher transcribed the audio transcripts and sent them to the participants to review, amend and approve.

## **Surveys**

The goal of triangulating the data initiated the qualitative findings being shared with a small, purposive sample through the use of a quantitative survey. Six Resource Teachers of the Deaf (RTDs) and six Advisers on Deaf Children (AODCs) from the lower half of the North Island and the length of the South Island were recruited to complete a self-administered survey (Appendix 4). The surveys were handed to six RTDs and two AODCs at a cluster meeting/conference and the remainder surveys were emailed to three AODCs at their place of work. The surveys were either returned by hand, or via email or post.

The survey utilised Bronfenbrenner's (1979) paradigm as its framework and involved a Likert scale with 18 statements being drawn from the hearing siblings' interview questions. The hearing siblings' responses and the inverse of their responses were used as statements to explore the AODCs' and RTDs' understanding of the hearing siblings' experiences of having a deaf child in the family. The statements encompassed hearing siblings' perceptions of their deaf sibling and their relationship, parental attitudes and expectations, society's view of deafness, prejudice, caregiving responsibilities, communication within the family, growing up with a deaf sibling and having a sibling lose their hearing later in life, relationships with extended family, career pathways and relationships with the Deaf community. Three of the survey's statements are:

Hearing siblings view their deaf sibling as "typical" or "normal".

Parents do not have the same expectations for their deaf and hearing children.

It doesn't matter whether a sibling is deaf from birth or becomes deaf later in life – the hearing sibling's relationship with his deaf sibling and his view of deafness is still the same.

The information collected from the survey was used to triangulate the data with the objective of gaining a broader, equalizing response to the research questions. The benefit of using self-administered surveys is that participants can answer them at their leisure and without the influence of others around them (Franklin, 2013). The quantitative data revealed that AODCs described their level of involvement with hearing siblings of deaf children over recent and past years as average to significant, while RTDs neither agreed nor disagreed with their involvement being described as average to significant.

## **Analysis of Data**

There are numerous ways of coding but all methods have the objective of enabling the researcher to streamline and concentrate on certain aspects of the data (Richards & Morse, 2007). Coding must always be for an objective and never a conclusion in itself as a researcher's intention is to learn from the data until he sees and comprehends patterns and explanations (Richards, 2009). Coding enables the researcher to become familiar with the data and is a much more problematic task if the transcriber has not conducted the interviews themselves (Richards & Morse, 2007). In this study descriptive, topic and analytical coding were used when analysing the data. The interview transcripts were analysed using colour coding with a number of key themes being identified.

### **Descriptive Coding**

Descriptive coding is mainly utilized in quantitative research, however qualitative research also necessitates a consciousness of setting (Richards & Morse, 2007). Descriptive coding is typically used for asking questions of the data, such as, did women and men view an event differently? Unless carefully controlled descriptive coding can lead to excessive information that can make the data difficult to view coherently (Richards, 2009). In the descriptive coding phase of this study the researcher stored information about the participants' gender, age and setting.

### **Topic Coding**

Topic coding is used in most qualitative research (Richards & Morse, 2007). It is used to assign passages of data to topics and is the first phase in more explanatory work

and the development of analytical categories (Richards, 2009). In this study topic coding involved the researcher establishing a category and recognizing where it fit in amongst the accruing ideas. The researcher was then able to review and reflect on the material using colour coding and from it develop analytical categories.

## **Analytical Coding**

Analytical coding in this study involved the researcher thinking about the significance of the data in context, establishing new groupings that articulated new thoughts about the data and coding to collect and contemplate all the data related to them (Richards & Morse, 2007). Typing the interview transcripts herself rather than sending them to a third-party to be transcribed helped the researcher to develop a sound knowledge of the data.

When analyzing the data collected from the questionnaires the researcher assigned a numerical value to each response. A bar chart was then created displaying the number and percentage of respondents who expressed agreement, disagreement etc. Last of all the Likert scale was summarized using the mean, i.e., the mean being the average value of the numbers assigned to the responses.

## **Conclusion**

This chapter examined the researcher's rationale for utilizing qualitative, quantitative and mixed methods research in answering the research question. An explanation was provided around the participant recruitment process, the collection of data by means of



interviews and questionnaires and the method used in analyzing the data. The following chapter examines the findings that emerged from the data collection.

## **Chapter 4**

### **Findings**

#### **Introduction**

The aim of this study was to answer the main research question “What are the experiences of hearing siblings when there is a deaf child in the family?” This chapter examines the findings gathered in pursuit of answering this question.

This study had five main objectives. The first objective was to examine the experiences of hearing siblings who had either grown up with a deaf sibling or whose sibling had lost their hearing later in life. The second objective was to consider the influence that parents and extended family members had on the hearing/deaf sibling relationship. The third objective was to establish whether society’s perceptions of disability complemented the sibling/family’s perceptions and what impact, if any, this had on the hearing/deaf sibling relationship. The fourth objective was to determine whether hearing siblings and their families formed connections with the Deaf community and what those connections involved. The fifth objective was to triangulate the data and establish whether there was commonality between the views of hearing siblings, Resource Teachers of the Deaf and Advisers on Deaf children.

During the study both qualitative and quantitative data were collected. In the qualitative phase semi-structured interviews were conducted with a purposive sample of four female and two male hearing siblings aged between 18-65 years living in the South Island of New Zealand. Five of the hearing siblings had brothers or sisters who were deaf from a young age and one sibling had a brother who lost his hearing in his early 40s. This qualitative data will be shared through the use of quotes and interpretative analysis.

Bronfenbrenner's (1979) ecological model was used as an analytical framework to classify the themes that emerged from both the qualitative and quantitative phases of the study and terms from this model will be used as headings in the following sections.

During the analysis of the interview transcripts 9 key themes were identified through the coding analysis described in Chapter 3. These were:

- relationships (sibling, parental and extended family);
- parental expectations, aspirations for the future and concerns;
- influence on personal development;
- communication;
- hearing siblings' and society's view of deafness and disability, prejudice, inclusiveness and self-comparisons;
- relationships with peers;
- influence on choice of career;
- connections with the Deaf community and deaf siblings attending residential schools;
- sharing information about deaf siblings' hearing loss, Government assistance and deaf related events in the community.

The following section examines the findings of the six participants who were involved in the study:

- Chloe, a female in her 60s whose younger brother lost his hearing later in life.
- Chris, a male in his 30s whose younger sister communicated in NZSL.
- Kelly, a female in her 20s with a younger brother with a cochlear implant.

- Penelope, a female in her 30s who had several deaf siblings who all communicated in NZSL.
- Ani, a female in her 30s who had a younger brother who communicated in NZSL and who also had additional needs.
- John, a male in his 20s with a younger brother with a cochlear implant.

## **Bronfenbrenner's (1979) Ecological Theory of Human Development: The Microsystem (family, classroom and immediate environment in which a person is operating)**

The first level of Bronfenbrenner's (1979) ecological model, the microsystem, refers to the environment in which an individual lives. This includes experiences with immediate family, extended family, friends and school peers. The microsystem is where an individual experiences the most social interactions (Bronfenbrenner, 1979). The individual helps to create or construct the experiences they have rather than purely witnessing or permitting things to happen to them. In this study the themes identified within the microsystem include relationships (sibling, parental and extended family), parental expectations, aspirations for the future and concerns, influence on personal development and communication.

### **Theme 1: Relationships (sibling, parental and extended family)**

The data collected during this study suggested that the deaf/hearing sibling relationship had a significant and diverse influence on the lives of all of the participants. First and foremost, each of the participants described their experience of growing up with a

deaf sibling as typical or normal within the immediate family circle. Participants spoke about the sense of normalcy they developed from an early age and subsequently grew up with and this was attributed to their parents' attitudes. This aligns with research by Marks et al. (2005) which found how parents respond to their disabled offspring has an important influence on the way siblings will relate to their disabled siblings. Parental influence is strong in how siblings view their disabled brother or sister as attitudes towards the disabled sibling mirror that of the parents (Verte et al., 2003).

During the quantitative phase of the research data was collected in a survey of Resource Teachers of the Deaf (RTDs) and Advisers on Deaf Children (AODCs) in the North and South Islands of New Zealand. The quantitative data revealed that RTDs and AODCs strongly agreed with the concept that parental attitudes had a strong influence on the type of relationships hearing and deaf siblings formed. Children imitate their parents' behavior in their exchanges with siblings (Pike, et al., 2005).

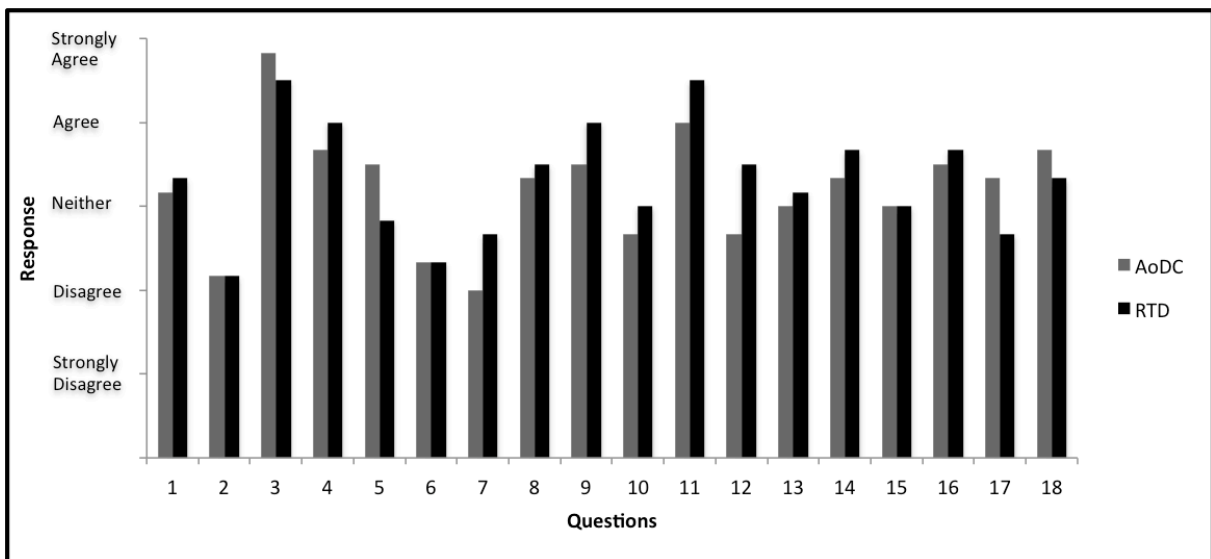


Figure 2: Mean responses by Advisers on Deaf Children and Resource Teachers of the Deaf.

Within the immediate family, participants said that they were given no reason to think their family was different or unusual. In the following quotes Ani, who had a younger brother who communicated in NZSL and who also had additional needs and John, who had a younger brother with a cochlear implant, describe the typical relationship they had with their deaf sibling.

Well to me it was normal because I was only 2 when he came along and so we just grew up with it (Ani).

Just typical brothers I guess. He was the little one. He was as annoying as hell!

Whenever I had mates over he was always there being a pain in the arse. Pretty typical...but as he got older he was just like a normal brother I guess. I didn't really have anything to compare it against but to me it just didn't seem any different really (John).

Research has generally portrayed the experiences of hearing siblings as negative (Tattersall & Young, 2003). This was certainly true for one participant, Chloe, whose brother lost his hearing later in life with the change in circumstances being viewed as a tragic and life-changing event. However, in recent years researchers have become uneasy about studies that focus primarily on pathology and unhealthy families and this has resulted in a shift towards reporting on families' intrinsic power and use of external support systems (Luckner & Velaski, 2004).

The data suggested that sibling relationships were open to change at significant stages of an individual's development. The sibling relationship is the longest relationship individuals will experience in their lifetime and the dynamics of that relationship alter and

can be more significant at different stages of the life span. This has been noted during transition periods such as childhood to adolescence and adolescence to adulthood when relationships become more voluntary and peer-like (Whiteman et al., 2011). One participant in the study, Chris, whose younger sister communicated in NZSL, stated that adolescence was a time of self-identity and self-determination and maintaining a relationship with his deaf sibling during that period did not hold the same level of importance as before. Chris acknowledged in the following quote that the teenage years were a time when the siblings headed in different directions.

It's interesting because I think my experience sort of changed as I grew up. So I think initially it didn't really feel that different and I didn't consider myself to be different or our family to be different. Really, it was just we had one sister who was deaf and that was it, it was quite normal initially and that was probably until I got to my teenage years. Then after that I think more in my teenage years I went through that whole individualization stage of a teenager and wanting to have it my way and all of that (Chris).

The data suggested that there was a notable difference between how participants viewed a sibling who grew up with a hearing loss and a sibling who lost his hearing later in life. Participants who grew up with a deaf sibling did not describe the experience as being filled with grief or involving feelings of substantial loss. Neither did these hearing siblings have to rapidly adjust their relationship with their deaf sibling and establish a new relationship. Conversely, Chloe, whose brother lost his hearing later in life, described how the entire family had to make adjustments and allowances for the deaf sibling's feelings of

isolation, anger and marginalisation. In the following quote she talks about the anguish she felt for her brother upon losing his hearing.

It had a hugely devastating effect on him and we all felt for him, we all felt very sorry for him because of the impact that it had on his life (Chloe).

The data from the quantitative survey suggested that RTDs and AODCs were unaware of how hearing siblings viewed their deaf sibling. The majority of responses neither agreed nor disagreed with the statement that hearing siblings viewed their deaf sibling as “normal or typical”.

The participants in the study reported that the relationship they had with their parents was uniformly strong and positive and having a deaf sibling did not have a negative influence on that relationship. The data revealed that participants believed that having a common purpose drew the family closer together. The quantitative data suggested that both RTDs and AODCs were uncertain as to whether hearing siblings believed that having a deaf child in the family brought the family together. However, with a deaf child in the family, family members develop increased resiliency, improved communication capabilities, compassion and acceptance (Salisbury, 1987). From the following quotes it is possible to gain some insight into the common purpose that brought the family together that the participants in this study were referring to.

Probably as a family we were quite close because we had that to bring us all together and we did a lot of traveling and things as a family for all of my brother’s hearing appointments and things (Kelly).



It probably made us closer. We are a very very close-knit family. I suppose we have had to be with all the medical procedures and things that he has gone through, illnesses and bits and pieces that there were times where we just had to stick together (Ani).

While participants reported that their relationship with their parents was generally positive and strong, there were occasions when participants felt that their sibling received more parental attention or favouritism. When there is parental differential attention in families with a child with a disability typical siblings feel envious and bitter because parents tend to spend more time with their disabled sibling (Russell et al., 2003). Participants in this study acknowledged that typical sibling rivalry did occur, together with feelings that being deaf gave the sibling a slight advantage, as the following quotes illustrate.

With my dad I could see the favoritism, I felt that it was favoritism, she could do no wrong in his eyes. All the kind of discipline came my way and if something went wrong my sister would be quick to point the finger and say that I started it. So therefore I would get disciplined. But I just took that on board. So I suppose I did have a little bit of resentment for her for abusing the relationship that she had with my dad by getting me into trouble. I saw it she was coming off the good girl and I was coming off the bad girl. But in effect it was the other way around! (Penelope).

I think he got away with it a bit more because he was deaf. I think he knew pretty early that he had a string he could draw on or tug on when he wanted. He got let off

with things a lot easier. If I did the same thing to him I wouldn't have stood a shit show! (John).

While there is limited research on typical sibling rivalry, it has been noted that typical siblings engage in wide-ranging social comparisons between themselves and their siblings, including how their parents deal with them as opposed to their siblings (Whiteman et al, 2011). While some participants in the study believed that their deaf sibling got away with a little more than they did the data showed that some participants rationalized and accepted their parents' actions because they viewed their deaf siblings' needs as being greater than their own. This aligns with other studies which found that while siblings with a disability receive more attention from parents, typical siblings do not see this as preferential treatment but more as a legitimate response to the additional caretaking needs of their disabled sibling (Stoneman, 1998). This quote from Chris, whose younger sister communicated in NZSL, demonstrates his level of acceptance and lack of resentment towards his deaf sibling.

But I think looking back I can really see that there was a lot of effort put in with my sister to make sure that she had access to language and education and there was a lot of intensive speech therapy initially and perseverance with hearing aids for quite a while until it was found that it was ineffective. Yeah there was a lot of focus on my sister but yeah I don't think we ever felt neglected at all. But I think it was obvious there was a lot of focus in that area (Chris).

The data showed that the relationship between the immediate family and extended family was at times typical but could also be complicated and challenging. Participants

reported that grandparents found it problematic to communicate with their deaf siblings and as a result the hearing sibling frequently ended up acting as an interpreter. This prevented hearing siblings from enjoying a relationship with their grandparents purely for themselves. One participant, Chris, highlighted his guilty feelings for having a conversation with his grandparents when his deaf sibling was not included, but then he also felt guilty neglecting his grandparents when he was preoccupied with his deaf sibling. The following quote illustrates the conundrum he sometimes faced.

We just had a fairly normal relationship with our grandparents. The only impact I can see is later on when my sister became much older then quite often I would have to interpret for grandparents or extended family. If I was around my grandparents when my sister was there I would almost slip into kind of like an interpreter/communicator mode so it wasn't just myself with my grandparents during those times. That was more later on though I think. Yeah, I think I was fairly torn with that because I felt very obligated to my sister knowing that her whole world was normally full of frustration, not being able to understand and not being able to communicate. But, then wanting to also have a relationship of my own with my grandparents as well, so being a bit torn between the two. I think sometimes I would neglect her if there was an interesting conversation going on and then other times I would feel like I was neglecting my grandparents because I was interpreting for her (Chris).

The data suggested that while grandparents were very caring and keen to form a relationship with the deaf sibling oftentimes the communication barrier made it just too difficult. As a result some grandparents became distant figures in the siblings' lives.

Participants in the study who were either older or younger than their deaf sibling talked about feeling responsible for their deaf sibling. Parents believe that younger siblings take on the role of older sibling. The more noticeable the disability, the sooner the caretaking began (Hames, 2008). Participants in this study felt a responsibility for their deaf sibling even when both of the siblings were in their grandparents' care. Similarly, a study by Greenspan (2001) found that siblings could become very protective of their disabled sibling to the point that they fretted about his wellbeing. This is clearly apparent in the following quote from Ani, who had a younger brother who communicated in NZSL and who also had additional needs.

...I remember, I know they would invite us both to go and stay but then they weren't quite sure how to deal to some of his (deaf sibling's) needs. Whereas mum and dad were hoping that they would just sort of figure it out and make do for the night and they would get the night off something would go wrong and I'd be sort of worried that they didn't know what they were doing and I'd say ring mum and say pick him up. It was more me wanting to be protective of him, making sure that he was okay but being too young to realize that he will be okay and mum and dad need the break. But I think I still had a good relationship with my grandparents it was just when you went visiting you were a little bit more protective and possibly I didn't run off and just go off and do things on my own. You sort of had to make sure it was suitable for him as well. My other grandmother sort of just fitted in. She used to live locally and would drive into the city and just stay the night or something to be there on Christmas morning. She just fitted in a bit more and she was very protective of him (Ani).

The findings of the quantitative survey indicated that RTDs strongly agreed and AODCs agreed that hearing siblings frequently took on responsibilities that their same aged peers were not required to. While household responsibilities for typical younger siblings generally do not increase, they do experience a rise in their childcare responsibilities (Crapps et al., 1991).

Some siblings like Penelope, who had several deaf siblings who all communicated in NZSL, had a close and warm relationship with their grandparents where the communication barrier was surmounted. The following quote highlights how a close relationship enabled Penelope's grandmother to be the first person to notice that her sibling had a hearing loss.

Grandmother...She was very close to our family...she was the one that picked up that my sister was deaf. She mentioned "I think there is something wrong" to my dad and my mum (Penelope).

When considering relationships with extended family, other than grandparents, the data suggested that these relationships were sometimes difficult and led to divisions within the family. Research by Pollard et al., (1999) supports this idea that certain family dynamics may occur in families where one or more children differ in hearing status and that the hearing status differences..."can be a cherished aspect of a family's diversity or a stage upon which family conflicts are acted out" (p. 156). As described in the following quote a lack of understanding of disability formed a barrier between the siblings and extended family members in this study.

His (my father's) brothers and sisters, we pretty much don't have a lot to do with and I would say some of that is due to the fact that they (my parents) had the disabled

child and chose to keep him and raise him instead of putting him into a home. A lot of them have never really “got” that...I don’t really know a lot of my dad’s side because we could never go to the family events because it was always like the old fashioned family picnic. Well, my brother couldn’t go or if we did go you’d go and you’d only be able to stay for about an hour cos by then (a medical condition necessitated) that it just wasn’t fair to him to leave him there (Ani).

The quantitative data suggested that RTDs agreed that hearing siblings would state that relationships with extended family members (grandparents, aunts/uncles) were generally positive when there was a deaf child in the family. AODCs were less certain with the majority of advisers neither agreeing nor disagreeing with the statement. A Canadian study by Dyson (2010) noted that parents of children with a learning disability often felt unsupported by extended family members.

**Summary: Theme 1 - Relationships (sibling, parental and extended family):**

- Within the immediate family, growing up with a deaf sibling was viewed as typical and normal.
- A sibling losing his hearing later in life was viewed as a traumatic event that negatively influenced the dynamics of the sibling relationship.
- Hearing siblings described their relationship with their parents as strong.
- Sibling rivalry and parental partiality did occur, but did not negatively impact relationships with siblings or parents.

- Grandparents were keen to form relationships but the communication barrier meant that some grandparents became distant figures in the siblings' lives.
- Hearing siblings often interpreted and felt guilty their deaf siblings could not interact with grandparents in the same way.
- Lack of awareness around disability created a rift between some participants and extended family members.
- Hearing siblings matured more quickly as a result of taking on responsibility for their deaf sibling's wellbeing and happiness.
- RTDs and AODCs strongly agreed that parental attitudes had a strong influence on the type of relationships hearing and deaf siblings formed.
- RTDs and AODCs were unaware of how hearing siblings viewed their deaf sibling.
- RTDs strongly agreed and AODCs agreed that hearing siblings took on responsibilities their same aged peers were not required to.
- RTDs and AODCs were uncertain whether hearing siblings believed that having a deaf child in the family brought the family together.
- RTDs agreed that relationships with extended family were generally positive when there was a deaf child in the family, while AODCs were less certain.

## **Theme 2: Parental expectations, aspirations for the future and concerns**

Participant interview data suggested that parents held the same expectations for their deaf and hearing children. This contrasted with the data collected from the quantitative survey where AODCs agreed that parents did not have the same expectations for their deaf

and hearing children and RTDs appeared to be uncertain about parental expectations for both siblings as they neither agreed nor disagreed.

Depending on the deaf sibling's current level of well-being, some parents' expectations focused on the here and now rather than on the future as this quote from Ani who had a younger brother who communicated in NZSL and who also had additional needs, demonstrates.

He had all these milestones and they were so set that he was going to prove everybody wrong and they sort of went through, and so they weren't focusing so much I think on where he would be in 30 years, they were focusing on you are never going to walk, yes you are! I still remember my mother's complete disbelief when he walked one day and he was 6 before he first walked and she didn't believe me when I said he was walking around the house. We've got photos, the neighbours came over to take photos of the moment he walked! It was those little milestones where you sort of see all their hard work with all the extra effort and things were all worthwhile (Ani).

For some parents their long-term expectations for their deaf child differed over time, with one parent frequently setting higher goals than the other.

Over time that changed a lot. Early on the expectations of my brother were pretty low. My father had high expectations for my brother, but my mother not so much. She was more looking at the he's disabled side of things and sort of playing things down for him. I know he got out of work around the house a lot. Other than that dad had high expectations for him and that was no different... I know between me and my sister, there's just something about him that he's going to be a multimillionaire or



something, he's as lazy as hell, there's just something about him that one day he is just going to be loaded just like that. I guess our expectations of him are pretty high (John).

When obstacles were identified some parents directed their energies into overcoming the challenges one step at a time and inspired their children to believe that anything was achievable, as this quote from Ani highlights.

The same. Basically the same with variation, I mean obviously there were things that were limiting factors for my brother doing things but rather than going "oh he'll never do that" my parents always looked at it and decided let's figure out a way to do it, how can we achieve this and what can we do? I always had the normal expectations, I had my chores, I had my schoolwork and my homework and all those sorts of things, you know and my manners. I suppose there was the extra expectation that you would look out for him but then I think any older sibling is expected to look out for the younger one to a certain extent...(Ani).

Parental expectations involved siblings completing their housework or homework tasks, watching out for each other, thinking about their future and choosing a rewarding career. Parents expected all of their children to do well at school and regularly encouraged their offspring to think about the future. This equitable treatment of the siblings reinforced the sense of normalcy within the family. In the following quotes the siblings describe the ordinariness and evenhandedness of their parents' expectations.

I think that expectations were pretty much just standard really. They expected us to behave well, they expected us to do our homework and think about our future and all

that sort of stuff. I don't think there was a difference with my deaf sister and with the rest of us. I wouldn't say there was a difference between expectations of the hearing siblings and deaf sibling at all (Chris).

I think expectations were similar (Penelope).

They (parents) just treated him like any normal child. They had the same expectations for him as they did for me. He didn't get any special treatment (Kelly).

The data suggested that parents were keen to ensure that all of their children were treated equitably. Parents consistently navigate decisions and trade-offs to ensure that all of their offspring feel their needs are equitably met (Evans, 1998). Participants in the study noted that if their deaf sibling received a gain then their parents would provide the hearing sibling with an equivalent item or experience to redress the balance. When parents treat siblings equally, adult sibling relationships are more likely to be positive (Boll et al., 2003). In the following quotes two participants described how their parents attempted to maintain a level playing field between the siblings.

If I needed something mum would always buy me something because my brother got quite a lot of funding for his cochlear implant and the deaf benefit or whatever it is they get, things like that (Kelly).

But then my parents also went out of their way to make sure that I got my driver's license really early because that gave me a bit more freedom to go out and go to the beach with my school friends or do things...So by having a car and having my

license early I got a bit more of my independence back. They did do a lot of things to make sure that where I missed in some areas I gained in others to sort of balance things out (Ani).

The findings revealed that the participants were aware of the different issues that their parents worried about with regard to their deaf sibling. In particular parents were concerned about the deaf sibling's ability to communicate with peers, his inclusiveness in learning environments and society in general, academic achievement, bullying, future employment and the expense attached to the deaf sibling's assistive devices becoming damaged. Parents can be anxious about how their child will function in the normal world, how their family and friends will respond and what the experience of having a deaf child will do to the remainder of the family (Meadow-Orlans, 1990). The following quotes illustrate the parental concerns that the participants in this study were aware of.

I think they always worried about schooling, both academically and socially. That was always an issue for my sister was the social aspect at school, just because being in our hometown she was always the only deaf person in the school (Chris).

Just the worry that any parents have about their kids, but especially one with a disability that he would get picked on (Kelly).

...Other than that it was damaging his cochlear (implant/processor). We had quite a few instances that happened, times when he fell into the river, smacked his head on something, they were always a bit of a worry. Equipment was the main issue (John).

It was just more for them (deaf siblings) to get a job. They were concerned that it was going to be difficult for them to get a job in their small town. So when it came to the end of their high school years that's when my dad made the decision to uproot us all and move to the city. For me that was particularly hard because I was 14 or 15 at that stage. I remember writing a letter to my mum saying "please, please no I don't want to go, I am going to miss all my friends", kind of playing that card (Penelope).

**Summary: Theme 2 - Parental expectations, aspirations for the future and concerns**

- Parents generally had the same expectations for their deaf and hearing children.
- Some parents focused on the here and now rather than the future.
- Sometimes parental expectations differed with one parent setting higher levels than the other.
- Some parents dealt with challenges one step at a time and inspired their children to believe that anything was achievable.
- Equitable treatment of deaf and hearing siblings reinforced a sense of normalcy within the family.
- Parents tried to ensure there was equity when one sibling received items or experiences.
- Parents worried about a number of things, most notably the deaf sibling being excluded from society.
- Advisers on Deaf Children agreed that parents did not have the same expectations for their deaf and hearing children, while RTDs were uncertain.

### **Theme 3: Influence on personal development**

Even though the participants in this study described their experience of growing up with a deaf sibling as normal or typical the data suggested that hearing siblings did go through unique experiences that shaped their personal development. Most notably the hearing siblings discovered that society's view of their deaf sibling did not equate with their own or that of their immediate family.

Society did not regard their deaf sibling as either typical or normal and as a result hearing siblings became very protective of their deaf sibling and were even subject to bullying. In the following quote Ani, who had a younger brother who communicated in NZSL and who also had additional needs, describes the bullying she experienced from her peers.

It probably made me a lot more protective of him and I guess as I got older and other people started to be cruel to me because of him it affected me then...Like high school I had a couple of really rough years where people sort of met him and then decided that they didn't want to know me which I never held against him, I sort of took it as your ignorance your loss (Ani).

In a study by Burton et al., (1994) siblings affirmed that having a sibling with a disability helped them to "be more responsible, more tolerant, better see the good in others, develop a better sense of humor and be more flexible" (p. 182). Similarly, the data from this study showed that being responsible for a deaf sibling helped to mature participants more rapidly and hearing siblings felt this was the reason for them maturing sooner than their peers. Making sacrifices for their deaf siblings also developed their maturity.

Hearing siblings tend to be more tolerant of difference, more empathetic and mature (Luterman, 1987).

One participant in this study, Penelope, who had several deaf siblings who all communicated in NZSL, recounted the experience of having added responsibilities as a young child and the influence this had on her personal development.

My hearing brothers, well one of them in particular, when his friends used to ring and leave messages or I would answer the phone, they actually thought I was older than I was and that was because I had to make lots of phone calls (for my siblings and parents) and so I wanted to make sure that I didn't sound like a little kid (Penelope).

Another participant, Chloe, whose brother lost his hearing later in life, discovered that adversity could lead to a positive outcome with her professional life being enhanced by the experience of having a deaf sibling. This is illustrated in the following quote.

I think he and I actually got a bit closer over it because of my profession I understood what had happened to him and what he was going through and perhaps understood better than most how to communicate with him after he had lost his hearing. So I think we sort of grew a bit closer over that and I also had a better understanding of what he was going through and what he would go through when he had his cochlear implant... Yes it has increased my awareness of cochlear implants. It's made me realize how amazing the technology is and the benefits of it having seen the difference that it has made to him (Chloe).

The data revealed that the teenage years were a period of transformation during which participants established their self-identity. One participant, Chris, whose younger

sister communicated in NZSL, realized that he had pushed his deaf sibling away during his teenage years and this caused him considerable regret. While participants were growing up there were numerous opportunities for them to meet new people and visit new locations purely because their sibling was deaf. The following quotes from Ani and John, the latter with a younger brother with a cochlear implant, illustrate what these opportunities involved.

Some of those things I actually got to experience because of him. I got to meet Andrew Merhtens because of him. I've met a lot of different deaf people who you wouldn't have normally met in your normal social circle...The shows and bits and pieces that we got to go to. I got to go to Australia because of him at one point, it was good (Ani).

I mean the only thing that probably impacted me was the trips to the city all the time. Trips for his operation and a few check ups as well. But they were good fun so I can't say that was a bad thing (John).

### **Summary: Theme 3 - Influence on personal development**

- Participants and their immediate family viewed the deaf sibling as typical or normal while society viewed them as disabled.
- Some hearing siblings were subjected to bullying.
- Being responsible for a deaf sibling matured hearing siblings ahead of their peers.

- The teenage years were a time of self-identity when some hearing siblings distanced themselves from their deaf siblings.
- Having a deaf sibling enabled participants to meet new people and enjoy new experiences.

#### **Theme 4: Communication**

Parents determined the mode of communication used by the participants' families. All of the participants, bar one, learnt New Zealand Sign Language ("NZSL") from a young age, as the following quotes illustrate.

I remember we were 2 years old when we went to sign language classes...my parents very quickly decided that signing was the way for my brother (Ani).

By the time she was about 6 months' old our family got resources in Sign Language and started to sign with her and so her first language was Sign Language (Chris).

One participant, Penelope, who had several deaf siblings who all communicated in NZSL, described herself as being fully immersed in NZSL from having deaf parents and several deaf siblings and she rapidly became fluent in the language. Exchanges with family members are normally enhanced when a deaf child has at least one parent with a hearing loss or when parents frequently mingle with deaf adults (Hintermair, 2000).

Another participant, John, who had a younger brother with a cochlear implant, struggled to communicate with his sibling and it wasn't until the deaf sibling received a cochlear implant that the communication improved. One participant, Kelly, who had a younger brother with a cochlear implant, believed that the speech barrier and difficulties in



communicating with her sibling in the early years meant that their relationship was not as close as it could have been. The quantitative data suggested that AODCs and RTDs agreed that communication between deaf and hearing siblings was generally weak and had a negative impact on sibling relationships.

Kelly also noted that she generally spoke for her deaf sibling right up until his late teens in an attempt to smooth over awkward social situations. During the periods when communication was problematic, simply spending time together playing in the garden brought the siblings closer together. For one participant, Chris, communicating with his deaf sibling during his teenage years was too bothersome and as the following quote illustrates it was easier for him to distance himself from his deaf sibling.

...I think more in my teenage years I went through that whole individualization stage of a teenager and wanting to have it my way and all of that and so I think I found communicating with my sister to be a bit more of a hassle and would get in the way of my interactions with my friends and everything. So I seemed to shut off from her a bit during my teenage years I think (Chris).

Parents not only determined the mode of communication, they were also proactive in providing opportunities for family members and friends to learn NZSL with a view to as many people as possible communicating with the deaf sibling. Parents even ran sign language classes out of their lounge.

Some participants were acutely aware of their parents' anxiety around their deaf sibling being excluded from society because of an inability to communicate. Participants were aware that parental attention was often focused more heavily on their deaf sibling. However, none of the hearing siblings appeared to resent this because they believed that

their deaf sibling's needs merited the extra attention. One participant, Chris, whose younger sister communicated in NZSL, admired and respected his parents for their tenacity in fighting for his deaf sibling's right to have an NZSL interpreter in the high school environment. Data collected from the quantitative survey indicated that both RTDs and AODCs agreed that hearing siblings viewed their parents as seeking optimum outcomes for their deaf siblings. As the following quotes illustrate hearing siblings understood the fundamental desire their parents had for their deaf sibling to be treated equitably and not to be excluded.

I do know that there was a lot of attention that my sister got, very valid, because they wanted the communication to happen. So I could understand that (Penelope).

I think they always worried about schooling, both academically and socially. That was always an issue for my sister was the social aspect at school, just because being in our hometown she was always the only deaf person in the school. My parents fought quite hard for funding for interpreters for her high school years (Chris).

The data showed that generally it was challenging for deaf siblings to communicate with extended family members and consequently hearing siblings often acted as interpreters. Similarly, a study by Barr et al., (2008) found that siblings of children with a speech impairment frequently acted as interpreters for their siblings and this was deemed a form of protection from others. Some participants felt that there was a disconnection between their deaf sibling and their extended family because their relatives never really got to know their deaf sibling. Studies have indicated that family and sibling interactions are not always smooth due to family members not sharing the same communication mode as a

deaf child (Henderson et al., 1991). One participant in this study, Ani, who had a younger brother who communicated in NZSL and who also had additional needs, was determined that her future husband would learn NZSL so that he could communicate with her brother. With some participants, communicating in NZSL became so ingrained that it even became their language of choice as the following quote demonstrates.

I got told off because I was quite shy as a little kid and at one point someone asked me a question and I lost my nerve and instead of speaking it I signed the answer. I remember being told off that that was most inappropriate and that I shouldn't do that (Ani).

Other participants said how very proud they were of their deaf sibling and their language. A language many hearing siblings considered spellbinding and beautiful.

The participants in this study were aware of a number of professionals being involved in their deaf siblings' lives, including Resource Teachers of the Deaf, Advisers on Deaf Children, Speech Language Therapists, Audiologists, Cochlear Implant Surgeons, Cochlear Implant Habilitationists and medical employees. Researchers are aware that a range of professionals such as audiologists and intervention teachers come into a family's life and offer facts and suggestions that sometimes unintentionally weaken the parents' influence (Luterman, 1987). As a result parents and siblings often become forceful advocates for the deaf child (Mindel et al., 1987). Similarly, one participant, Chris, recalled his parents disagreeing with professionals about the most appropriate mode of communication for his deaf sibling. Going against expert advice was a difficult decision for his parents to make. Participants acknowledged that their parents were strong advocates for their deaf siblings as the following quote illustrates.

...there were a lot of professionals trying to force us as a family to have my sister speaking and using hearing aids and the family decided that that wasn't the right thing to do...they specifically said that the family was making the wrong decision and that she was going to fail, she is not going to achieve that way and then they came back a few years later and said "Oh, she's actually doing alright and saying whatever you are doing, keep doing it" and so it was bucking the trend...I'm very proud of the stand that they made with that really, I think it was the right thing to do (Chris).

When a hearing loss occurred later in life for one sibling this had a significant impact on his ability to communicate effectively with family, friends and colleagues and meant that he had to give up his career. The data suggested that the subsequent isolation for this sibling was more acute than for those siblings who grew up deaf. The other participants in this study who grew up with a deaf sibling did not appear to pass through the same kind of deficit model. The sudden change in personal circumstances had a hugely detrimental affect on the deaf sibling's well-being as the following quote from his hearing sibling, Chloe, illustrates.

I could see that it had affected him, his mood and his general wellbeing and that I think a lot of the time he was battling with depression over it (Chloe).

The quantitative data revealed that AODCs uniformly disagreed with the suggestion that it didn't matter whether a sibling was born deaf or became deaf later in life, the hearing sibling's relationship with his deaf sibling and his view of deafness was still the

same. RTDs appeared uncertain as to whether this was the case as they neither agreed nor disagreed with the statement.

In reality, there is a significant difference for siblings who have developed a relationship with their sibling before the ill health or accident occurs. These siblings feel the loss of their sibling, particularly if the relationship is affectionate and this sentiment can be ongoing (Joyce, 2011).

#### **Summary: Theme 4 - Communication**

- Parents primarily determined the mode of communication used by the family.
- Communication with deaf siblings was occasionally challenging, except when the family was fluent in NZSL.
- Communication with extended family was challenging with hearing siblings having to act as interpreters.
- Relationships with extended family members were often distant because of the communication barrier.
- Parents worried about the deaf sibling's ability to communicate and their child being excluded from society.
- Parents were strong advocates for their deaf children and sometimes chose to ignore advice from professionals.
- A sibling losing their hearing later in life was a traumatic event that left an individual feeling isolated, bereft and unable to communicate.
- AODCs and RTDs agreed that communication between deaf and hearing siblings was generally weak and had a negative impact on sibling relationships.

- RTDs and AODCs agreed that hearing siblings viewed their parents as seeking optimum outcomes for their deaf siblings.
- AODCs disagreed with the suggestion that it didn't matter whether a sibling was born deaf or became deaf later in life, the hearing sibling's relationship with his deaf sibling and his view of deafness was still the same. RTDs appeared uncertain as to whether this was the case as they neither agreed nor disagreed with the statement.

In summary, the findings of this study demonstrated that Bronfenbrenner's (1979) microsystem was the most crucial level within the ecological model. The microsystem had a fundamental role in developing the participants' temperaments and individual interactions. At the microsystem level parents championed a philosophy that constructively shaped the participants' attitudes, aspirations, principles, resilience and empathy. Participants became advocates for their deaf siblings in a society that predominantly considered their siblings disabled. The next level of Bronfenbrenner's (1979) model, the mesosystem, examines the connections between an individual's home and school or work.

### **The Mesosystem (connection between a person's home and school or work)**

The second level of Bronfenbrenner's (1979) ecological model, the mesosystem, refers to the various interactions between the microsystems. This may include experiences at home related to experiences at school or experiences at school related to experiences with community groups. Once more the individual actively helps create the experiences

rather than simply observing them. In this study the themes identified within the mesosystem include society's view of disability, relationships with peers and choice of career.

### **Theme 5: Hearing siblings' and society's view of deafness and disability, prejudice, inclusiveness and self-comparisons**

The data revealed that each of the participants in this study, with the exception of Chloe whose brother lost his hearing later in life, viewed their deaf sibling as typical or normal, "he's just my brother". Hearing siblings, when talking about their relationship with their deaf sibling, describe their connection as "normal" involving the sharing of common interests and archetypal sibling arguments (Tattersall et al., 2003). Participants in this study saw their family as being just like any other as the following quote illustrates.

For what was happening in our family it was just normal, everyday, this was just our family, this was how we worked, this was how we communicated and lived (Penelope).

When asked in the quantitative survey whether they agreed or disagreed with the statement that society viewed deaf children as "normal" or "typical", RTDs and AODCs disagreed with the statement. Researchers have rigorously debated the notion of being able to effectively measure societal attitudes towards disability and have concluded with all of its complexities it is impossible to make generalizations about society as a whole (Marini, 2012). There is an overabundance of empirical and anecdotal studies that support the view that attitudes towards individuals with disability are predisposed to being negative (Marini, 2012).

From an early age many of the participants in this study realized that society did not view their deaf sibling as either typical or normal but instead viewed them as disabled. This was also true for Chloe whose brother lost his hearing later in life. While most children do not attach a negative connotation to their sibling's disability they are aware of the experience of disability, with their disabled sibling encountering external barriers and discrimination and being treated differently from themselves (Stalker et al., 2004). Some participants in this study said that along with their deaf sibling they also encountered prejudice. Siblings are aware of disapproving responses to their disabled siblings including name-calling, staring, condescending comments and misguided sympathy (Thomas, 1999).

The quantitative data showed that both AODCs and RTDs agreed that hearing siblings, along with their deaf siblings, experience prejudice. One participant, Ani, who had a younger brother who communicated in NZSL and who also had additional needs, recalled her brother being prohibited from visiting her primary school and this meant that the family could not come and watch her play sport. Another participant, Kelly, who had a younger brother with a cochlear implant, recalled feeling frustrated that her deaf brother felt the need to disguise his assistive devices so that his peers would not tease him or ask intrusive questions. The following quote illustrates Kelly's exasperation.

Some people just really need a kick up the bum is all I have to say! People sort of notice anything that's different. When he first got his newest cochlear he had the magnets you could change, you could change the colour on them and he would always have a brown one so it didn't stand out because he didn't want people to notice it and point out and say "What's that?". Yeah definitely eh, know all about



that! You know what kids are like at school, it's not just specifically one kid it's anyone that's different (Kelly).

The data showed that each of the participants had a deeply ingrained sense of social justice that involved a steadfast belief that society should treat their deaf siblings equitably. The participants stated that their parents modeled this philosophy of equitable treatment and respect for all individuals. One participant, Penelope, who had several deaf siblings who all communicated in NZSL, in the following quotation describes her father's deep sense of social justice, his belief that society should not regard deafness as a disability and that deaf people should have the same fundamental rights as everyone else.

With my father, he was a very strong advocate for deaf people. So anything that was in the paper about "deaf and dumb" he would be writing letters to the Editor "They are not dumb!" all that sort of thing...My dad did fight really hard for the rights of deaf people, for them to have that respect within the community. I think he developed that because of the need to do the best for his family. He was really good at that kind of academic writing letters to the Listener and other newspapers saying "that's not appropriate in this day and age. I have a deaf daughter and I don't consider her to be disabled, it's just going to be a challenge for her but she's just like anybody else". So there was a lot of that from him in the outside wider community (Penelope).

Some participants reported instances where some individuals in society lacked a degree of awareness or sensitivity. Chloe, the hearing sibling whose brother became deaf later in life remembered an occasion when her sibling was presented with an award by his

colleagues. To both siblings' incredulity the deaf sibling was given a music CD. Chloe was astonished that no allowance was made for the fact that her sibling had lost his hearing.

Some participants in the study did not experience any form of prejudice in the learning environment and noted that schools made a particular effort to include children with disabilities, as the following quotes demonstrate.

In primary school they (children with disabilities) were just treated the same as everyone else really (John).

I don't remember it (discrimination) ever happening for me anyway in my educational experience. But I do think that the schools were very good with my sister when she was in classes. The classes would learn basic Sign Language and they would learn specific, just I suppose little tips for communicating with a deaf person, how they have to be looking at you and that sort of thing. So yeah I think the attitude was very good from the school, definitely (Chris).

While the data revealed that participants were aware of the differences between their family and other families, none of the participants said that they envied their peers, compared their families or wished that they could change their personal circumstances. However, the quantitative data suggested that both AODC's and RTDs were uncertain as to whether hearing siblings were resilient and tended not to be negatively affected by or resentful of changes that occurred in their lives as a result of having a deaf child in the family. Resilient families have the ability to convert hazards into contests, unpleasant experiences into learning opportunities and unyielding public attitudes into

accommodating attitudes (Antonovsky, 1987). As the following quote from Chris, whose younger sister communicated in NZSL, illustrates, participants in this study appeared genuinely happy with family life.

Looking back I don't ever remember feeling my situation was a negative one in comparison to my peers (Chris).

Participants attributed the characteristic view they had of their deaf sibling and family to their parents modeling and living the philosophy that they were, first and foremost, an ordinary, typical Kiwi family. One participant, Ani, who had a younger brother who communicated in NZSL and who also had additional needs, summed this perspective up with the following quote.

It was my parents' attitude just in the sense that I never looked at my brother as a disability he was just my brother (Ani).

**Summary: Theme 5 - Hearing siblings' and society's view of deafness and disability, prejudice, inclusiveness and self-comparisons**

- Hearing siblings realized from an early age that society did not view their deaf sibling as either typical or normal but instead viewed them as disabled.
- Some participants encountered prejudice towards themselves and their deaf sibling while others did not experience any discrimination.
- Participants had a deeply ingrained sense of social justice that comprised a steadfast belief that society should treat their deaf sibling equitably.

- Participants realized that there were differences between their family and their peers' families but they did not feel envious or wish that they could change their personal circumstances.
- Participants felt that their parents modeled and lived the philosophy that they were a typical, normal Kiwi family and as a result their offspring adopted the same beliefs.
- RTDs and AODCs disagreed with the statement that society regarded deaf children as “normal” or “typical.
- AODCs and RTDs agreed that hearing siblings, along with their deaf siblings, experienced prejudice.
- AODC's and RTDs were uncertain as to whether hearing siblings were resilient and tended not to be negatively affected by or resentful of changes that occurred in their lives as a result of having a deaf child in the family.

### **Theme 6: Relationships with peers**

The data revealed that having a deaf sibling did have an impact on participants' relationships with their peers. One participant, Ani, stated that during her time at high school classmates ostracized her purely because they considered her deaf sibling to be “weird”. Some participants were acutely aware that society did not view their deaf sibling in the same way they did. Siblings are guarded about which friends they trust and who they will talk to about a disabled sibling (Hames, 2008). Siblings do not want their friends to meet their disabled siblings because they are worried that their brother or sister will be dealt with shabbily or treated inequitably (McHale et al., 1986). The data showed that

participants in this study were highly selective in the friendships they fostered and would only choose those who would accept their deaf sibling, as the following quote from Penelope, who had several deaf siblings who all communicated in NZSL, illustrates.

I was very selective in who I brought home. I didn't want to bring home people that were going to make fun of my family. I knew that my family was different. When I was much younger probably not knowing what the difference was because for me it was just normal. So I was very selective in the friends that I had who actually came home with me. I was just worried about the teasing (Penelope).

One participant, Chris, whose younger sister communicated in NZSL, said that he could not recall any problems with the interactions between his friends and his deaf sister. While two other participants, John and Kelly, who both had younger brothers with a cochlear implant, noted that the difference in age and the fact that the siblings attended different schools meant that their friends and deaf siblings did not cross paths. While Chloe, the participant who had a brother who lost his hearing later in life did not experience any impact on her own friendships from having a deaf sibling, as the following quote illustrates she found it very hard to observe the negative influence on her brother's social life.

The social impact for him was severe too and we felt very sorry for him over that as well because he and his wife were quite social. He would just sit with his wife and he wouldn't attempt to make much social interaction and nobody would attempt to make it with him because I just assumed that he wouldn't hear them. Isolating, very isolating for him I think (Chloe).

### **Summary: Theme 6 - Relationships with peers**

- Participants would only choose friends who would accept their deaf sibling.
- Society did not easily accept deaf siblings and occasionally this led to hearing siblings being ostracized by their peers.
- Some participants experienced no difficulties in interactions between their friends and deaf siblings.
- Some participants' friends did not cross paths with their deaf sibling because of the difference in age and the fact that they attended different schools.
- A hearing loss rendered some siblings socially isolated.

### **Theme 7: Influence on choice of career**

The data revealed that some participants specifically chose to work with the deaf because they grew up with a deaf sibling. Other siblings were adamant that their career would have no connection with deafness. The quantitative data indicated that while RTDs agreed that siblings frequently ended up working in deaf related careers, AODC's were less certain that this was the case and neither agreed nor disagreed with the proposition.

One sibling, Chloe, who had chosen her career before her brother lost his hearing felt very proud to be involved in deaf education and described in the following quote how her brother's deafness directly benefitted the children she worked with.

My brother's experience made me quite proud of what I was doing. It brought it close to home. Deafness can happen to anybody and in a way I think it helped me to relate better to my students, especially the ones who have got cochlear implants. I will often tell them I've got a brother with a cochlear implant. They are always interested and want to know how old he is, when he got his cochlear implant and so

on... it confirmed for me that the job I do working with deaf children is very worthwhile (Chloe).

Siblings who enter the disability field conclude that they would probably never have chosen that career path if it weren't for the fact that they grew up with a disabled sibling (Marks et al., 2005). One participant in the study, Chris, whose younger sister communicated in NZSL, believed his decision to train as an NZSL interpreter strengthened his relationship with his deaf sister. In the following quote Chris describes how having a deaf sibling and training as an NZSL interpreter brought the siblings closer together and literally changed his life.

...So I studied for 2 years and then have been working as an interpreter for just over 10 years now... So I think our bond has just increased right through since I left home I suppose, we've got closer and closer. So I think for her, almost me doing that and taking it quite seriously into the next step was quite a sort of a validation of her as a person...I would have been an accountant. It definitely changed my life (Chris).

#### **Summary: Theme 7 - Influence on choice of career**

- Some participants chose a career working with the deaf, while other participants specifically chose not to.
- Those participants who chose to work with the deaf said that the experience of having a deaf sibling had a positive influence on their working relationships, brought them even closer to their deaf sibling and changed their lives.
- RTDs agreed that siblings frequently ended up working in deaf related careers while AODC's were less certain that this was the case.

In summary, the findings of this study showed that Bronfenbrenner's (1979) mesosystem was the second most crucial level within the ecological model. The mesosystem highlighted the juxtaposition between a society that views the deaf siblings as disabled and the family that views the deaf siblings as normal or typical. Within the immediate family experiences were often unique with parents doing their utmost to ensure that their children were treated equitably. The data from the mesosystem revealed that to a certain extent participants lived a double life. One life where acceptance and equality were a given and another life where acceptance and equality often had to be advocated for or earned. The next level of Bronfenbrenner's (1979) model, the exosystem, examines the environment in which a person is not involved.

### **The Exosystem (environment in which a person is not involved)**

The third level of Bronfenbrenner's (1979) ecological model, the exosystem involves the individual playing no part in the construction of experiences. Rather the experiences have a direct influence on the microsystems the individual is involved in. In this study the themes identified within the exosystem include interactions with the Deaf community and school placement for deaf siblings.

### **Theme 8: Connections with the Deaf community and deaf siblings attending residential schools**

The data showed that all of the participants in this study formed a connection with the Deaf community at some stage of their deaf sibling's life. Parents were keen for their deaf children to meet other deaf children and deaf adults and to feel part of both the deaf



and hearing worlds as this quote from Penelope, who had several deaf siblings who all communicated in NZSL, demonstrates.

I think it was a Friday night. Everyone that had deaf children would bring a plate. There would be supper and we would have tea and coffee and we would play table tennis or indoor bowls or just sit and have a chat. It was an opportunity for the parents and the families, the siblings and the deaf kids to get together. We would have Christmas dinners and go out to restaurants (Penelope).

The parents' desire for their children to be able to communicate in NZSL initially forged the connection but even when the deaf child's mode of communication changed the families still maintained some form of contact over time. Some of the participants' parents held core positions in various Deaf organisations and clubs and as a result some hearing siblings developed even stronger links with the Deaf community.

The sibling who lost his hearing later in life also chose to involve himself in the Deaf community. His sister Chloe noted that he wrote articles on his experience of receiving a cochlear implant and gave talks to other deaf people who were on the cochlear implant waiting list.

Hearing siblings described their initial interactions with the Deaf community as quite strange and unusual with everyone signing, but later it seemed a more normal aspect of their family life. Participants stated that there were many Deaf social gatherings that their whole family attended and participants were aware that their parents' objective was for their deaf sibling to establish friendships with other deaf children. Some of the connections tapered off as the years went by with two participants noting that this was certainly the case around their teenage years. The quantitative data showed that AODCs and RTDs were uncertain as to whether hearing siblings tended to become actively

involved in the Deaf community with their hearing siblings. Hearing siblings' lives are enriched by learning sign language, meeting other deaf people and interacting with the Deaf community (Ladd, 1988).

One participant, Ani, who had a younger brother who communicated in NZSL and who also had additional needs, recalled her parents receiving support from members of the Deaf community and her parents adopting the Deaf community's philosophy that deafness was not a disability and therefore did not need to be fixed. Parents highlight the importance of receiving support from the immediate family, extended family, community and professionals they work with (Meadow-Orlans et al., 2003). In the following quote Ani refers to the assistance her family gratefully received.

I think my brother had involvement in some sense with the deaf community as soon as mum and dad realized he was deaf because it's one of those things, they never saw his deafness as something that you had to fix...They (parents) sort of figured that we have been given this kid for a reason and he's deaf for a reason and he's going to need to talk and so he is going to need to sign...He was always involved with the signing and a lot of the older deaf got involved with helping mum out (Ani).

The data revealed that Ani had a sibling who was a day student at a residential school and Penelope had a sister who boarded at a residential school. Penelope said that having her sister live in a residential school did not have a noticeable impact on their relationship but she was aware of several activities and events that she missed out on that her deaf sister had the opportunity to attend purely because she boarded in a residential school. Living at home also brought with it additional responsibilities that Penelope believed her deaf sister would not have been given while boarding in a residential school as the following quote illustrates.

With my dad's job my mum and I would help... You know clean all the windows and all that sort of that stuff. But I was responsible to mow the lawns and help my mum clean and empty the rubbish bins at the place of work. After school I was going straight to a job to do my chores and that is how I got my pocket money. Whereas I know my sister would not have had that responsibility (Penelope).

**Summary: Theme 8 - Connections with the Deaf community and deaf siblings attending residential schools**

- All of the participants formed a connection with the Deaf community that was mainly driven by their parents' desire for their deaf sibling to learn to communicate and develop friendships.
- For some participants the teenage years meant a change in attitude and they chose not to maintain a connection with the Deaf community.
- Some parents gratefully received assistance from the Deaf community and adopted their philosophy that deafness was not something that needed to be fixed.
- Some deaf siblings attended a residential school for the deaf and participants stated that this did not have an impact on their sibling relationship.
- Some participants were aware that their deaf sibling had the opportunity to attend more events and activities than they did while living at home and that they had more household responsibilities than their deaf sibling living in residential accommodation.
- AODCs and RTDs were uncertain as to whether hearing siblings tended to become actively involved in the Deaf community with their hearing siblings.

In summary, the findings of this study showed that although Bronfenbrenner's (1979) exosystem level did not appear to have as comprehensive an influence on the participants' lives as the microsystem and mesosystem levels it still shaped many of the participants' fundamental, day-to-day experiences. In particular the exosystem level highlighted the relentless, steadfast drive parents had for ensuring that each of their children had access to all of life's opportunities. One of those opportunities included making links with the Deaf community and opening the doors of the Deaf and hearing worlds to all of their children. The final level of Bronfenbrenner's (1979) model, the macrosystem, examines the larger cultural context.

### **The Macrosystem (the larger cultural context)**

The fourth level of Bronfenbrenner's (1979) ecological model, the macrosystem involves the influence society or culture has on an individual. The influences can be political or religious. In this study the themes identified within the macrosystem included sharing information about deafness, Government assistance and deaf related events in the community.

#### **Theme 9: Sharing information about deaf siblings' hearing loss, Government assistance and deaf related events in the community**

The data revealed that participants were aware of their sibling's deafness and what that involved but not every participant could remember who it was in the family that shared information about their sibling's hearing loss. Some participants believed it was their parents while others said it was a matter of them simply "knowing" rather than having questions answered and issues confirmed. One participant, John, who had a younger

brother with a cochlear implant, was certain his parents would have shared some information about his brother's hearing loss when his sibling received a cochlear implant. Another participant, Penelope, who had several deaf siblings who all communicated in NZSL, said she never asked questions about her sisters being deaf simply because it wasn't an issue for her. Chloe, whose brother lost his hearing later in life noted that discussions about his hearing loss were generally discouraged. Chloe stated that her brother did not like to talk about it and would become irascible. Some parents however spoke freely with the hearing sibling about their deaf sibling's hearing loss, as the following quote from John illustrates.

...when I was little they would have explained stuff but I'm quite close with my father and that and he's open talking about cochlears and I know there's a few issues with the new one and we just openly discuss that sort of stuff. Just chatting generally (John).

Parents of children with disabilities report that enlightening typical siblings about a disabled sibling is never a one-off occurrence and has to be repeated over time (Hames, 1997, 1998). The quantitative data from this study indicated that RTDs agreed that parents shared information about their deaf child with the hearing siblings, while AODCs were uncertain as to whether this occurred, neither agreeing nor disagreeing.

Each of the participants in the study noted that their family received Government funding when their sibling was diagnosed with a hearing loss. This lifted a tremendous burden off the family in terms of paying for travel costs to appointments, purchasing and maintaining assistive devices, CI surgery and habilitation. Participants were aware that without Government funding their family would not have been able to access those products and services. Children with disabilities more commonly reside in homes with

earnings below the poverty line than children who are free from disability (Fujiura et al., 2000). One participant, Ani, recalled her parents having an ongoing battle to gain funding for an NZSL interpreter for her deaf brother. In the following quote Chloe describes the life-changing impact on her brother when he received financial assistance for a cochlear implant that he would never have been able to afford for himself.

They were very good to him, he got plane fares paid for and everything under the grant and the operation paid for of course; I think it is about \$50,000 isn't it? He wouldn't have been able to pay for that himself...I was sad that he had to give up a career that he enjoyed. Happy that his cochlear implant has been so successful and has worked out so well for him (Chloe).

The quantitative data suggested that neither AODCs nor RTDs were certain whether hearing siblings were aware of financial strains being placed on the family in meeting the needs of their deaf sibling.

The data showed that at different stages of their lives many of the participants were aware of and took part in deaf-related events occurring in the community. These included watching television programmes or movies involving deaf characters, attending worldwide deaf sporting events, visiting Deaf clubs and associations, being knowledgeable about Deaf Awareness Week and watching NZSL interpreters appearing on television and interpreting for officials during the Christchurch earthquake news bulletins. As the following quote from Penelope, who had several deaf siblings who all communicated in NZSL, illustrates, parents were constantly keeping in mind the need for their deaf child to improve his communication skills and establish meaningful relationships.

...Also the World Deaf Games that were in Christchurch, we came to those as a family as well, just as part of getting my sister involved in the Deaf community (Penelope).

The quantitative data revealed that both AODCs and RTDs agreed that hearing siblings generally had an awareness of deaf-related events happening in the community.

**Summary: Theme 9 - Sharing information about deaf siblings' hearing loss, Government assistance and deaf related events in the community**

- Some parents shared information about the deaf sibling's hearing loss with participants, but others said they just had a sense of knowing.
- Each of the participants' families received financial assistance from the Government and this was invaluable in securing products and services for the deaf sibling.
- One set of parents had an ongoing battle to receive funding for an NZSL interpreter for their deaf son.
- Participants were aware of and took part in deaf related events in the community, such as Deaf Awareness Week, with parents wanting the deaf sibling to develop his communication skills and form meaningful relationships.
- RTDs agreed that parents shared information about their deaf child with hearing siblings, while AODCs were uncertain as to whether this occurred and marked the statement as neither agree nor disagree.

- AODCs and RTDs were uncertain whether hearing siblings were aware of financial strains being placed on the family in meeting the needs of their deaf sibling.
- AODCs and RTDs agreed that hearing siblings generally had an awareness of deaf-related events happening in the community.

In summary, the findings of this study showed that the final level of Bronfenbrenner's (1979) ecological model, the macrosystem, appeared to have the least influence on the day-to-day experiences of hearing siblings. The data suggested that the most significant aspect of the macrosystem for hearing siblings was possibly the financial assistance that their deaf siblings received from governmental agencies. For hearing siblings its significance was measured in terms of the stress relief it afforded their parents. The data revealed that parental influence which encompassed their deeds, boundless tenacity and lifelong philosophy emerged at every level of Bronfenbrenner's (1979) ecological model and had a significant influence on the experiences of hearing siblings with a deaf child in the family.

In the following chapter the significance of the findings of the qualitative interviews and quantitative survey will be discussed against the background of relevant literature. The limitations of the study and proposed future direction for research will be outlined and conclusions will be drawn on the implications for practice.



## **Chapter 5**

### **Discussion**

#### **Introduction**

This thesis reports on the experiences of hearing siblings when there is a deaf child in the family. Very little has been written about the experiences of hearing siblings and the little research that has been undertaken has generally portrayed the experiences of hearing siblings as negative (Tattersall et al, 2003). In addition, there is a scarcity of research on the experiences of hearing siblings whose brother or sister has lost their hearing later in life as opposed to during childhood. Research has tended to focus on the experiences of parents of deaf children and children of deaf adults rather than the experiences of hearing siblings. Murphy (1979) suggests, “The small amount of literature concerning the brothers and sisters of handicapped children is symptomatic of a lack of professional interest and investment” (p. 353).

This study had five main objectives. The first objective was to examine the experiences of hearing siblings who had either grown up with a deaf sibling or whose sibling had lost his hearing later in life. The second objective was to consider the influence that parents and extended family members had on the hearing/deaf sibling relationship. The third objective was to establish whether society’s perceptions of disability complemented the sibling/family’s perceptions and what impact, if any, this had on the hearing/deaf sibling relationship. The fourth objective was to determine whether hearing siblings and their families formed connections with the Deaf community and what those connections involved. The fifth objective was to triangulate the data and establish whether there was commonality

between the views of hearing siblings, Resource Teachers of the Deaf and Advisers on Deaf children.

The following chapter interprets the results of the study against a background of existing literature utilizing a theme-by-theme summary of the main points that emerged from the interviews and questionnaires. The implications of the research for families, educators and service providers supporting hearing and deaf siblings are considered. Limitations of the study and the future direction for research in this area are also reflected upon.

### **The experience of having a deaf sibling and the influence of parents and extended family**

Much of the literature that currently exists on the experiences of hearing siblings suggests that having a deaf sibling in the family has a negative influence on hearing siblings' relationships and their quality of life (Tattersall et al., 2003). The findings of this study differ from this premise with participants describing their experience of growing up with a deaf sibling as normal, typical and for the most part commonplace. This supports the research of Stalker et al., (2004) who discovered when siblings were asked to describe their disabled sibling, young children did not refer to disability at all and older children explicitly said that they did not see their disabled sibling as different, instead many described their sibling as "normal". This rationalizes Luckner et al.'s (2004) suggestion that in recent years researchers have become uneasy about studies that focus primarily on pathology and unhealthy families and there has been a shift towards reporting on families' intrinsic power and use of external support systems.

The probable origin of the participants' optimism in this study was the significant influence parents exerted in encouraging hearing siblings to view their relationship and experiences with their deaf sibling as normal or typical. This is apparent in the following quote from a participant, Ani, who had a younger brother who communicated in NZSL and who also had additional needs.

It was my parents' attitude just in the sense that I never looked at my brother as a disability he was just my brother (Ani).

Parents set a positive tone early on in the siblings' lives encompassing a fundamental belief that the family, despite its relative uniqueness, was still very much a typical family as the following quote from Penelope, who had several deaf siblings who all communicated in NZSL, demonstrates.

For what was happening in our family it was just normal, everyday, this was just our family, this was how we worked, this was how we communicated and lived (Penelope).

This is consistent with Youngstrom et al.'s (2003) findings that an abundance of broad familial support, optimism within the parent-child relationship and unswerving parental discipline all buffer children and adolescents from the turmoil that can be caused by life events. These findings also support Boll et al.'s (2003) research that when parents treat siblings equally, adult sibling relationships are more likely to be positive.

One could surmise that if the parents in this study had instead emphasized the differences between their children and had held different expectations for each of the siblings

it is probable that the hearing siblings would not have viewed their sibling relationship and their family in such a positive light. This proposition is consistent with findings by Bat-Chava et al., (2002) who noted when parents make pessimistic comparisons between their hearing and deaf children by highlighting the capabilities of the hearing sibling this can negatively affect the relationship of the deaf and hearing siblings. It also aligns with the findings of Verte et al., (2003) that parental influence is strong in how typical siblings view their disabled brother or sister as attitudes towards the disabled sibling mirror that of the parents. Siblings in this study felt that having a deaf sibling united the family. As one participant, Ani, noted in the following quote.

It probably made us closer. We are a very very close-knit family (Ani).

In line with Marks et al.'s (2005) research, this study found that how parents respond to their disabled offspring has an important influence on the way siblings will relate to their disabled siblings.

Parental differential attention in families with a child with a disability leaves siblings feeling envious and bitter because their parents tend to spend more time with their disabled sibling (Russell et al., 2003). However the findings of this study do not support this premise. While there were occasions when hearing siblings believed that their deaf sibling received preferential treatment from their parents purely because of his hearing loss, hindsight appears to have enabled the siblings to accept these past events with a degree of irony as the following quote from John, who had a younger brother with a cochlear implant, suggests.

I think he got away with it a bit more because he was deaf. I think he knew pretty early that he had a string he could draw on or tug on when he wanted. He got let off

with things a lot easier. If I did the same thing to him I wouldn't have stood a shit show! (John).

This aligns with Bat-Chava et al.'s (2002) findings that although parents were aware that the hearing sibling vied for their attention, they frequently found it challenging to accommodate the needs of both their hearing and deaf children.

The findings also revealed that the family's sense of unity did not uniformly apply to the teenage years with some hearing siblings describing this period as a time when they were detached from their deaf sibling. This aligns with the findings of Wilson, McGillivray & Zetlin (1992) who suggest that the acceptance of disability changes throughout the life cycle. In the following quote Chris, whose younger sister communicated in NZSL, highlights the change in his attitude.

... my experience sort of changed as I grew up...Really, it was just we had one sister who was deaf and that was it, it was quite normal initially and that was probably until I got to my teenage years. Then after that I think more in my teenage years I went through that whole individualization stage of a teenager and wanting to have it my way and all of that" (Chris).

This supports the research of Raghuraman (2008) who suggests that during the teenage years hearing siblings can feel self-conscious about being with their deaf sibling in the presence of their peer group. In the present study, the reason for the hearing siblings' change in attitude was inconclusive, however one possibility could be a societal pressure to conform

to the status quo during a time when hearing siblings had a heightened awareness of their developing self-identity and did not want to stand out from their peers.

There may also have been a desire to be free from responsibility and to express thoughts and feelings that were contrary to parental views. The findings did not reveal any specific strategies parents used to navigate these complex teenage years or even whether parents were aware that some teenage hearing siblings went through a phase of detachment from their deaf sibling. It is hoped that these findings will raise parental awareness of the possibility of sibling detachment during the teenage years and encourage parents to seek assistance, if required, in identifying strategies to manage challenging teenage sibling relationships.

The findings in this study revealed that relationships with extended family members were often mixed as the following quotes demonstrate.

It was probably their attitude, they saw him as the disability, and the typical deaf/dumb not worth my time attitude, whereas we sort of looked at him as, I never looked at him as a disability I looked at him as my brother (Ani).

For them (my grandparents) they always tried to keep up with my brother... (John).

It was apparent from the findings that the inability of deaf siblings to communicate easily with extended family members and the hearing siblings having to act as interpreters sometimes prevented strong familial relationships from forming and left some participants feeling unsupported by their relatives. A sense of disquiet is highlighted in the following quote from Chris, whose younger sister communicated in NZSL.

...later on when my sister became much older then quite often I would have to interpret for grandparents or extended family because they weren't able to sign. If I was around my grandparents when my sister was there I would almost slip into kind of like an interpreter/communicator mode so it wasn't just myself with my grandparents during those times (Chris).

This aligns with the findings of Dardeen (2008) who suggests that hearing siblings and families with a deaf child must make noticeable changes in their structure and function in order to communicate and interact with other family members.

### **Implications for practitioners**

Parents of children with a learning disability often felt unsupported by extended family members (Dyson, 2010). When parents settle on the most appropriate communication mode to use with a deaf child grandparents may not be part of the decision-making process. If parents choose sign language as the most suitable mode of communication the immediate family may be able to access resources and services that support the learning of sign language. However, these resources and services do not generally extend to grandparents and other family members. Families who live in isolated regions will be even less likely to receive assistance. We live in an era where both parents are likely to be working full-time and grandparents are taking on a greater role in raising their grandchildren. Support services for children with disabilities currently provide assistance to parents but this does not, as a matter of course, extend to grandparents and other family members. Such assistance could be central in developing and maintaining the vital support network of families with children

with disabilities and agencies could be reflecting on the level of support that is currently provided to extended family members.

In 2010 the New Zealand Ministry of Education carried out a Review of Special Education services New Zealand wide. The Review sought input from parents, families and the special education sector. The Ministry of Education's Funded Supports and Services for Learners with Special Education Needs/Disabilities (2012) paper noted that the findings of the Review signaled the need to:

- increase inclusive practices in schools;
- raise achievement for learners with special education needs/disabilities;
- reduce bureaucracy and make special education services (provided by the Ministry and schools) easier for parents and whanau to access and navigate (p. 2).

While the Ministry's (2012) paper stated that there was an increasing expectancy that children with disabilities would achieve and succeed alongside their peers, there appeared to be no consideration or acknowledgement of the role that siblings could play in helping children with disabilities to achieve that success.

The findings revealed that none of the participants in the study indicated that they received opportunities to establish strong connections with other hearing siblings. While some participants did meet other hearing siblings at social events with deaf families, in general there was no mention of significant relationships being forged over time. In New Zealand an emphasis has been placed on CODAs (Children of Deaf Adults) making connections with other CODAs but this does not appear to have been generalized to hearing



siblings of deaf children. The reason for this could be the scarcity of research around hearing siblings and the low profile they hold in society's and deaf education's psyche.

Significantly, the findings from this study indicated that when stepping outside the immediate family, hearing siblings sometimes felt marginalized, bullied, misunderstood and incredibly protective of their deaf sibling. Without the opportunity to make links with other hearing siblings participants said they sometimes felt isolated and estranged. Agencies and services working closely with families of deaf children, such as AODC's, RTDs, Deaf Education Centres, Cochlear Implant Habilitationists, Parents of Deaf Children Associations and Social Workers are in a suitable position to be able to recognize the important role hearing siblings play in the lives of their deaf siblings and to set up support groups or organise events that would enable hearing siblings to connect with one other.

### **The perception that society and hearing siblings have of disability**

When asked to describe some of the issues that their parents worried about with regard to their deaf sibling, hearing siblings generally described issues within society as opposed to within the family, including communication with peers, inclusiveness in learning environments, bullying and the possibility of future employment. Parents can be anxious about how their child will function in the "normal" world (Meadow-Orlans, 1990).

The findings from this study suggest that some sectors of society continue to view disability in an unfavorable light. When the hearing/deaf siblings and their families intermingled with extended family or individuals in society, "difference" often assumed a negative connotation. This was highlighted in the following quote from Ani, who had a younger brother who communicated in NZSL and who also had additional needs.

...my first primary school I got shifted out of because they refused to let my brother on the property. The staff. So my parents couldn't even come down to watch my school sports or anything because the school just didn't want him on the property, didn't want him around.” (Ani).

There is an overabundance of empirical and anecdotal studies that support the view that attitudes towards individuals with disability are predisposed to being negative (Marini, 2012). When 15 disabled adults were interviewed about their experiences growing up they revealed that during early to middle childhood they realized that society held them in low regard. In complete contrast, the disabled adults' families treated them as typical siblings, permitted them to take chances and were crucial in their developing positive identities, a sense of worth and autonomy (Singer, 2002).

In spite of the lack of widespread affirmation from society, the participants in this study reported that their parents actively sought, fostered and achieved a state of normalcy for themselves and their children. When disability comes into the family it throws the family system into disarray, but just for a limited time. In due course the family system reinvents itself, adapting to the “new normal” and it is family resilience that enables this to happen (Marini, 2012).

Before commencing this study the researcher hypothesized that hearing siblings would view their experiences of growing up with a deaf sibling in a less than positive light. The researcher also did not foresee a significant contrast between the way hearing siblings and society for the most part viewed the deaf sibling. The findings from this study also suggest

that RTDs and AODCs working in the field of deaf education were unaware of how hearing siblings viewed their deaf sibling.

### **Implications for practitioners**

When supporting deaf children and their families do educators and service providers tend to operate from a deficit model, focusing on what needs to be fixed as opposed to a constructive model of what is working well and could be enhanced? One reason for this could be that working from a deficit model enables easier and more superior access to funding for the deaf child. The downside of focusing on the deficit model is that educators and service providers may be blinded to the fact that the family is in fact operating within a constructive model and there could be a mismatch between familial and professional perspectives and aspirations. As the following quote shows this was the experience for one participant in the study, Chris, whose younger sister communicated in NZSL, when his parents settled on a particular mode of communication for his sister.

...he (the Adviser) specifically said that the family was making the wrong decision and that she was going to fail, she is not going to achieve that way and then he came back a few years later and said “Oh, she’s actually doing alright and saying whatever you are doing, keep doing it” (Chris).

Findings such as these are important because they encourage professionals who are supporting families to reflect further on their professional practice, biases and assumptions and how these might influence the service they provide to hearing siblings and their families.

The family and ecological systems approach (Nichols & Swartz, 1998) depicts the family as an interactive system where what impacts one member of the family affects all members of the family. In New Zealand, typically the role of the RTD is to support the deaf child, parents and mainstream teachers and no additional funding is provided to encompass hearing siblings. The findings from this study suggest that when there is a deaf child in the family the hearing sibling has an integral role in supporting, mentoring, interpreting for and safeguarding the deaf sibling. The deaf/hearing sibling relationship is generally warm and close with much of what a deaf child learns and understands about their world being aided and achieved through the support of hearing siblings and parents. The diverse role of hearing siblings can be catalogued as playfellow, buddy, guardian, assistant, rival and parent surrogate (Atkins, 1987). These findings suggest that there is a case for hearing siblings to be given the opportunity to become more fully involved in the services surrounding deaf children as hearing siblings could be a crucial component in ensuring optimal outcomes. When families, teachers and professionals include siblings in educational and support-services, brothers and sisters become a significant component of family centred practices (McBride et al., 1993).

### **When a sibling loses hearing later in life**

Another unexpected finding in this study was the actuality that growing up with a deaf sibling was a vastly different experience to having a sibling lose hearing later in life. Hearing siblings in this study described the first experience as normal and the latter experience as tragic, traumatic and life changing. Currently, there appears to be little research on the experiences of hearing siblings when a sibling loses his hearing later in life.

The literature that currently exists focuses on an individual's hearing loss due to ageing. An Australian study in 2008 examined the connections between hearing loss, activity and involvement restrictions, happiness and health-related quality of life. The study found that cumulative hearing impairment in robust, community-based elderly people was linked with notable adverse effects on activities, involvement and wellbeing. Hearing loss later in life affected an individual's social communication, created anger and stress and lowered their quality of life (Hickson, Allen, Beswick, Fulton, Wolf, Worrall & Scarinci, 2008).

In this study however clear reasons were identified as to why hearing siblings' experiences in these two situations were so vastly different. Hearing siblings stated that losing your hearing later in life brought with it feelings of grief and loss for a life that had disappeared. Siblings feel the loss of their sibling, particularly if the relationship is affectionate and this sentiment can be ongoing (Joyce, 2011). Additionally, the findings from the present study revealed that rapidly adopting a new and successful mode of communication with family and friends was very challenging and the deaf sibling's employment status was also negatively affected.

### **Implications for practitioners**

Individuals and organisations in society do not easily accommodate or understand the changes and challenges that a hearing loss brings. This is a significant finding for when educators and service providers become more aware of the impact the two diverse situations have on a family they will be better equipped to provide high-quality support and access to the most suitable agencies for hearing siblings going through an intense grieving process.

The findings in this study revealed that hearing siblings were aware that their parents worried about their deaf sibling being included in society, particularly those deaf siblings in mainstream educational settings. While most children do not attach a negative connotation to their sibling's disability they are aware of the experience of disability, with their disabled sibling encountering external barriers and discrimination and being treated differently from themselves (Stalker et al., 2004). Siblings safeguard their disabled sibling from bullying and unfavorable friends (Barr et al., 2008). Some participants in this study wanted to protect themselves and their deaf sibling from unkind or heedless comments and as the following quote from Penelope, who had several deaf siblings who all communicated in NZSL, indicates they were judicious in their friendships.

So I was very selective in the friends that I had who actually came home with me. I was just worried about the teasing (Penelope).

Parents and hearing siblings in this study had a strong desire to lessen society's negative perception of difference and to facilitate universal acceptance. When a deaf child receives specialist teacher support from an RTD this can unwittingly reinforce society's perception of difference because children do not generally receive this kind of additional adult support. In a survey of 10,000 mainstream teachers, while more than two-thirds agreed with inclusion in principle, less than one third believed that disabled children would benefit from inclusion (Scruggs et al., 1996). Teachers felt that children with severe disabilities would have a detrimental affect on mainstream students. The findings from this study raise the question of what might best constitute inclusive practices in a mainstream educational setting. Historically, in New Zealand RTDs have tended to withdraw deaf children to work

one-to-one with them but there has been a growing awareness that this is not fundamentally an inclusive practice and tends to reinforce the perception of difference. Society's perception of difference and inclusiveness encountered in this study means that professional discussions around inclusive practice and the role of the RTD/AODC should be an ongoing and intrinsic element of teacher training programmes and in-house professional development.

### **Hearing siblings and their families making connections with the Deaf community**

The findings of this study support the suggestion that family and sibling interactions are not always smooth due to family members not sharing the same communication mode as a deaf child (Henderson et al., 1991). Exchanges with family members are normally enhanced when a deaf child has at least one parent with a hearing loss or when parents frequently mingle with deaf adults (Hintermair, 2000).

The findings revealed that each of the hearing siblings in this study maintained a connection with the Deaf community either intermittently or continuously throughout their lives. Additionally, all of the participants learnt New Zealand Sign Language (NZSL) to varying degrees and at different stages of their childhood and adulthood. One hearing sibling, Chris, whose younger sister communicated in NZSL, revealed that once he significantly improved his NZSL skills he began to appreciate his sister in a totally new way.

...when I became more fluent in Sign Language...I discovered this incredible personality in my sister that I had seen but I hadn't seen the depths of it I don't think (Chris).

Regrettably, despite NZSL being the third official language of New Zealand its use is steadily declining. According to Statistic New Zealand's census figures of 2013, since the census of 2006 the number of NZSL users from Gisborne to Southland has dropped by 16% and from Northland to the Bay of Plenty by 27%. The decline in use of NZSL could be viewed as a serious threat to the longevity of Deaf culture and the very existence of the Deaf community. This study's findings have shown that the desire to learn NZSL has generally been the first contact point between hearing families and the Deaf community. Without this connection young deaf people and their families would have no deaf role models or avenues to pursue when seeking to make connections and broaden their sense of self-identity.

### **Implications for practitioners**

As NZSL is the third official language of New Zealand there would seem to be an onus on the New Zealand Government and its agencies to provide effective opportunities and funding to enable deaf and hearing families to continue to learn and utilise NZSL. In keeping with Te Reo, another official language of New Zealand, every attempt should be made to keep NZSL alive for the benefit of all New Zealanders, either by funding NZSL classes at community colleges, funding special events during Deaf Awareness week to raise New Zealanders' awareness of our third official language and finally to encourage and support schools in utilising the New Zealand Sign Language Curriculum. Significantly, a German study involving 317 parents of deaf children found that parents who often interacted with other parents of deaf children and with deaf adults developed loving, accommodating and unquestioning relationships with their deaf children (Hintermair, 2000). The positive relationships that the hearing siblings in this study developed with the Deaf community



supports the findings of Ladd (1988) who suggests that hearing siblings' lives are enriched by learning sign language, meeting other deaf people and interacting with the Deaf community.

### **Limitations of the study and future direction for research**

Some limitations were identified within the study. The study involved 18 participants and as such could be considered a small sample. Although the sample was taken from both the North and South Islands of New Zealand it may not represent the experiences of all families with deaf and hearing siblings, including Maori and Pacifica families, as well as the experiences of RTDs and AODCs living in New Zealand. Maori participants were not specifically targeted in this study and no Maori participants indicated an interest in taking part. However, it is acknowledged that many Maori in New Zealand experience deafness in their whanau. As the full particulars of the deaf siblings' hearing loss were not revealed it is possible that the different types of hearing loss were not entirely represented, for instance deaf siblings with a mild to moderate hearing loss. However, this was not the focus of the study and might be an interesting aspect to explore in future research. There is also the possibility that providing information retrospectively may engender positive rather than negative recollections because time can mellow, rationalize or even provide duplicate experiences. The latter when linked to the participants' own experiences with their children may, for example, rationalize decisions made by their parents in years gone by. Recollections and events may also not be as crystal clear as they were on the day they occurred. It is also possible that participants who have been through positive experiences may be more willing to be involved in a study than, for example, participants who have been

through negative experiences. Having said that, one participant in the study, Chloe, whose brother lost his hearing later in life, was keen to share the traumatic experience that she and her family went through when her brother lost his hearing later in life.

Qualitative interviewing is not an instrument to be used to burrow for irrefutable information, rather it is a means of helping participants to relate their observations and experiences in ways that are significant and suitable to them (Tattersall et al., 2003). The findings presented here are the experiences and perceptions of those participants who chose to be involved in the study and their contributions are valid and valuable in shaping the services that governmental agencies, educators and other professionals provide to deaf children and their families.

This study was an initial examination of a theme that has received very little attention in New Zealand or internationally and accordingly may act as a stepping-stone for additional research to be undertaken in the future. Further research stemming from this study may include a more in-depth inquiry into the experiences of hearing siblings when a brother or sister loses their hearing later in life. Researchers may decide to interview younger hearing siblings rather than gathering information using a retrospective viewpoint. Researchers may also choose to make comparisons between the responsibilities given to older, middle and younger hearing siblings, male or female, or consider and compare the experiences of hearing siblings in purely signing or oral families. Further research might focus on the services provided in different countries to hearing siblings of deaf children and the agencies that exist to encourage and support connections between hearing siblings. Additionally, researchers could investigate the kinds of initiatives and opportunities service providers and agencies are providing for hearing children to experience meaningful, positive interactions

with children who are deaf or have a disability. Non-disabled and disabled individuals meeting in settings where there is common interest and equity helps society's attitude to be more positive towards disability (Marini, 2012).

## **Conclusion**

The first research question investigated in this study was “What are the experiences of hearing siblings when there is a deaf child in the family? This research question is important because very little is known in New Zealand or globally about the experiences of hearing siblings.

The study revealed that hearing siblings make a significant and enduring contribution to the lives of their deaf siblings yet they continue to have a low profile in society's and deaf education's psyche. The experience of growing up with a deaf sibling is for the most part a positive one. Conversely, the experience of having a sibling lose his hearing later in life is neither positive nor typical. Life for the hearing and deaf siblings is thrown into turmoil and hearing siblings go through a period of intense grief and change.

Those siblings who grow up with a deaf sibling view their brother or sister as normal or typical and apart from some situations where communication is challenging the deaf/hearing sibling relationship is similar to siblings in other families. Notably, in deaf families where everyone communicates in NZSL there does not appear to be any communication challenges within the immediate family. Challenges however frequently arise when extended family members such as hearing grandparents wish to communicate with the deaf sibling and hearing siblings are often called upon to act as interpreters.

Parents are strong advocates for their deaf children and this filters down to the hearing siblings. Parental influence is crucial in how hearing siblings view their deaf sibling and the sibling relationship as children adopt the behaviours and perceptions of their parents.

Hearing siblings are often aware that their deaf siblings receive greater parental attention but accept the status quo because they believe it to be justified. They also tend to be aware of the concerns their parents have around their deaf sibling, in particular being included in society and being accepted. Around the teenage years some hearing siblings become detached from their deaf siblings and for a period the relationship is not as close as before.

Within the immediate family hearing siblings view their deaf sibling as typical or normal but once they step outside the immediate family hearing siblings become aware of society's view of disability. Some hearing siblings experience inclusiveness and acceptance of their deaf sibling while others experience prejudice, obliviousness and bullying. This stark contrast means that hearing siblings are generally very protective of their deaf sibling and selective in the friendships and significant relationships they develop.

The desire to learn NZSL is often the initial contact families have with the Deaf community. Each of the families involved in the study made a connection with the Deaf community at some stage in their life and some connections were lifelong. The desire to communicate on a deeper level with their deaf sibling is sometimes the motivation for siblings to become NZSL interpreters. Other hearing siblings specifically choose not to have careers that bring them into contact with deaf people. Hearing siblings are often aware of Deaf community events and the assistance their parents receive from the Deaf community, education providers and governmental agencies. There is an acknowledgement that such

support reduces parental anxiety as well as financial worries connected with assistive devices.

Notably, the World Report on Disability (2011) by the World Health Organisation states that globally the lion's share of assistance and support services provided to people with disabilities comes from family members or networks. Siblings are crucial in the lives of individuals and families worldwide and across the life span (Whiteman et al., 2011). They act as companions, sounding boards and role models in childhood and adolescence (Dunn, 2007) and as resources of support throughout adulthood (Connidis et al., 1995). Siblings perform a vital role in families and researchers should continue to explore in greater detail the contributions that hearing siblings of deaf children make to the family system (Minuchin, 1974).

The second research question investigated in this study was “What are the knowledge and perspectives of Teachers of the Deaf/Advisers on Deaf Children about the influence on hearing siblings of having a deaf sibling?” Findings from the RTD and AODC surveys suggested that these professionals were for the most part unaware of how hearing siblings viewed their deaf sibling. AODCs also believed that parents did not have the same expectations for their deaf and hearing children, while RTDs were uncertain. Both AODCs and RTDs believed that communication between hearing and deaf siblings was generally poor and had a negative impact on the sibling relationship.

Each of these beliefs contrasted the views of the hearing siblings in this study. It is possible that these views are a result of the changes in the AODC role where less time is spent by AODCs in visiting the family home and coming into close contact with hearing siblings. RTDs typically do not visit the family home either. Significantly, AODCs in this

study disagreed with the suggestion that it didn't matter whether a sibling was born deaf or became deaf later in life, the hearing sibling's relationship with his deaf sibling and his view of deafness was still the same. RTDs appeared uncertain as to whether this was the case as they neither agreed nor disagreed with the statement. This finding is in stark contrast to the views of the hearing siblings and has important ramifications for providing services that effectively comprehend and meet the individual needs of families when a sibling loses his hearing later in life. There is however a shared awareness between AODCs and RTDs that society does not view disability in a positive light.

It is hoped that the findings of this study will encourage education providers, agencies and professionals in the field to recognize and appreciate the significant influence hearing siblings have in the lives of deaf siblings and the part they play in changing negative attitudes. Support services should be accessible to both hearing and deaf siblings and their parents (Antonopoulou et al., 2012).

The World Report on Disability (2011) advocates close collaboration between families and family organisations, governmental and non-governmental organisations in providing support to families. Ideally, service providers will begin to encompass hearing siblings in the assistance they provide to families of persons with a disability. Additionally, the World Report on Disability (2011) states that undesirable attitudes to disability are a key environmental factor that needs to be dealt with across all spheres. Contrastingly, the findings of this study have revealed that within the immediate family, disability as a concept holds no prominence. This could be attributed to parents providing equal and undivided attention to all siblings and a strong basis for the development of positive relationships between siblings (Mohd & Sarullah, 2010).

This study of the experiences of hearing siblings when there is a deaf child in the family has shown that hearing siblings view their deaf siblings as typical and normal, love and fully accept them for who they are and there is much that society can learn from their example.

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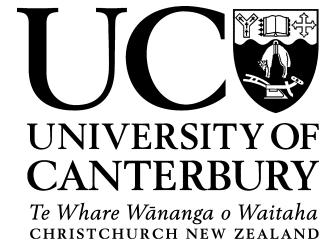


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## Appendices

### Appendix A: Information Letter



#### **The experiences of hearing siblings when there is a deaf child in the family Information Sheet for Participants**

Dear Sir/Madam,

My name is Liz Ray. I am a teacher of the deaf currently undertaking my thesis to complete my Doctor of Philosophy degree. My thesis will research the experiences of hearing siblings when there is a deaf child in the family.

I would like to invite you to take part in an individual interview on this topic. It is anticipated that the individual interview will take 2 to 3 hours. The individual interview will be audiotaped and the information collected will be transcribed at a later date. Direct quotes may be used from the individual interview in the summary analysis of information, but only if they do not identify the speaker. You will be sent a copy of the transcription that you will be asked to check and amend if necessary.

Information collected from the individual interviews will be analysed to determine common themes. At the completion of the study you will receive a summary of the findings. The researcher will ensure that this report does not contain any information that could identify you or your family. The final report will be presented for assessment in fulfilment of my Doctor of Philosophy degree and copies of the thesis will be bound and placed in the University of Canterbury library. The results of this study may be used to further professional development of education professionals and to support other families who have children who are deaf.

The information you provide will be treated confidentially and you will be asked to choose a pseudonym for yourself and your family. You have the right to withdraw from this study at any time up until final analysis of the information.

If you would like to take part in this study, please sign the attached consent form and return it in the enclosed envelope by [Day/Month]. All the data will be securely stored in password-protected facilities and locked storage at the University of Canterbury for five years following the study. It will then be destroyed.

If you would like any further information please contact me by telephone on: 389-4988, email [liz.ray@xtra.co.nz](mailto:liz.ray@xtra.co.nz), or either of my thesis supervisors as listed below:

- \* Dr Dean Sutherland, University of Canterbury, Room 226, Level 2, Waimairi Building, Private Bag 4800, Christchurch 8140, Ph: 366-7001, ext: 7176.
- \* Dr Billy O'Steen, University of Canterbury, Private Bag 4800, Christchurch 8140, Ph: 022 074 5296.

If you have a complaint about the study, you may contact the Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)).

I am looking forward to working with you and thank you in advance for your contribution.

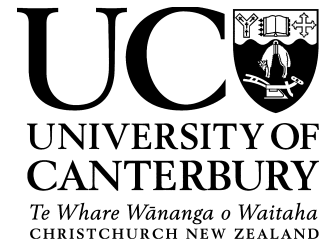
Yours sincerely

Liz Ray

## Appendix B: Consent Form

Telephone: 389-4988:

Email: liz.ray@xtra.co.nz



### **The experiences of hearing siblings when there is a deaf child in the family Consent Form for Participants**

I have been given a full explanation of this project and have been given an opportunity to ask questions.

I understand what will be required of me if I agree to take part in this project.

I understand that my participation is voluntary and that I may withdraw at any stage without penalty up until final analysis of the information.

I understand that any information or opinions I provide will be kept confidential to the researcher and that any published or reported results will not identify me.

I understand that all data collected for this study will be kept in locked and secure facilities at the University of Canterbury and will be destroyed after five years.

I understand that I will receive a report on the findings of this study. I have provided my email details below for this.

I understand that if I require further information I can contact the researcher, Liz Ray. If I have any complaints, I can contact the Chair of the University of Canterbury Educational Research Human Ethics Committee.

By signing below, I agree to participate in this research project.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Email address: \_\_\_\_\_

Please return this completed consent form to [name] in the envelope provided by [Day/Month].

## **Appendix C: Interview questions for participants**

### **The experiences of hearing siblings when there is a deaf child in the family**

#### Level 1: Microsystem

(The family, classroom, immediate environment in which a person is operating).

1. How would you describe your experience of growing up with a deaf sibling?
2. Do you think having a deaf sibling impacted upon you emotionally?
3. Do you think having a deaf sibling impacted upon your relationship with your parents?
4. Do you think having a deaf sibling impacted upon your relationship with extended family members, for example grandparents?
5. Can you comment on your communication with your deaf sibling?
6. Did your parents have the same expectations for you and your siblings?
7. Were you close to your deaf sibling when you were children?
8. Were you aware of any special concerns your parents had about your deaf sibling?

#### Level 2: Mesosystem:

(The connection between a person's home and school or work)

1. Did having a deaf sibling impact upon your interactions with your peers at school?
2. Did having a deaf sibling impact upon your academic achievement at school?
3. Do you feel that having a deaf sibling made you more aware of prejudice?
4. Did you feel you were different from your peers at School? In what way?
5. Did you feel your family was different from other families? In what way?
6. Did teachers at your school provide opportunities for children to develop an awareness of, or improve their interactions with children with disabilities?

7. Did having a deaf sibling impact upon your career choice?

Level 3: Exosystem:

(Environment in which a person is not involved)

1. Did your deaf sibling go to a residential school?
2. Did this have an impact on your relationship with your deaf sibling?
3. Did this have an impact on relationships within the family?
4. Did your sibling or your family have any involvement with the Deaf community?
5. Did you have any connections with other deaf people?

Level 4: Macrosystem:

(The larger cultural context)

1. Was any information about your sibling's deafness shared with you?  
What information was shared? How was it shared?
2. Was there an impact on your family in terms of Government funding and your family's financial resources in meeting the needs of your deaf sibling?
3. Were you aware of deaf-related events that happened in the community, for example Deaf Awareness week, deaf characters in television programmes, the World Deaf Games?



## Appendix D: RTD and AODC survey

The title of my PhD thesis is “**What are the experiences of hearing siblings when there is a deaf child in the family?**” In my first teaching role in deaf education I taught for 5 years in a bi-lingual pre-school for deaf children and their hearing siblings. During that time I observed the ease with which pre-school hearing siblings code switched between New Zealand Sign Language and English when communicating with deaf or hearing children/adults. This made me question what further impact having a deaf sibling had on hearing siblings. In completing this questionnaire your identity will remain fully anonymous and the information gathered will be used solely to identify similar or contrasting views to those provided by the hearing siblings who participated in my study. Thank you very much for taking part.

**Please tick ONE box in each line.**

	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
1. Hearing siblings view their deaf sibling as “typical” or “normal”.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Society views deaf children as “typical” or “normal”.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Parental attitudes have a strong influence on the type of relationships hearing and deaf siblings form.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Hearing siblings view their parents as proactive in seeking optimum outcomes for their deaf sibling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Parents do not have the same expectations for their deaf and hearing children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Communication between hearing and deaf siblings is generally weak and has a negative impact on sibling relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. It doesn’t matter whether a sibling is deaf from birth or becomes deaf later in life – the hearing sibling’s relationship with their deaf sibling and their view of deafness is still the same.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please tick ONE box in each line.**

	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
8. Hearing siblings note that relationships with extended family members (grandparents, aunts/uncles) are generally positive when there is a deaf child in the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Hearing siblings do experience prejudice towards their deaf sibling and themselves.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Hearing siblings are resilient and tend not to be negatively affected by, nor resentful of, changes that occur in their lives as a result of having a deaf child in the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Hearing siblings often take on responsibilities that their peers are not required to have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Hearing siblings frequently end up working in deaf-related careers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Hearing siblings tend to become actively involved in the Deaf community with their deaf siblings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Parents share information about their deaf child with the hearing siblings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Hearing siblings are not aware of any financial strains being placed on the family in meeting the needs of their deaf sibling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Hearing siblings generally have an awareness of deaf-related events happening in the community.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Hearing siblings believe that having a deaf child in the family brings the immediate family closer together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I would describe my level of involvement with hearing siblings of deaf children over recent and past years, as average to significant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please add your reflections on working with deaf children and the experiences of their hearing siblings:**

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